

IMPROVING SERVICES TO HANDICAPPED CHILDREN

WITH EMPHASIS ON HEARING AND VISION IMPAIRMENTS

PREPARED FOR THE DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE,
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R-1420-HEW
MAY 1974

Rand
SANTA MONICA, CA. 90406

The research described in this report was sponsored by the Department of Health, Education, and Welfare, Office of the Assistant Secretary for Planning and Evaluation, under Contract No. HEW-OS-72-101. Reports of The Rand Corporation do not necessarily reflect the opinions or policies of the sponsors of Rand research.

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PREFACE

This is the second of two Rand reports that together constitute a comprehensive, cross-agency evaluation of federal and state programs for assistance to handicapped children and youth. The Rand Corporation performed the study under Contract No. HEW-OS-72-101 at the request of the Assistant Secretary for Planning and Evaluation of the U.S. Department of Health, Education and Welfare. The results of the study are intended for use by the Assistant Secretary and other federal officials, by state agencies, by associations representing the handicapped, and by the general public.

The study pursues two broad purposes defined for it by HEW officials. The first is to describe current federal and state programs for service to mentally and physically handicapped youth in the United States, to estimate the resources devoted to various classes of handicapped youth, and to identify major problems with the present service system. The second is to help HEW officials improve the system as a whole by evaluating current policies, and to improve the delivery of services to hearing and vision handicapped youth in particular by suggesting alternative future policies.

This report concentrates on the second purpose. Its companion piece, R-1220-HEW, *Services for Handicapped Youth: A Program Overview*, May 1973, concentrated on the first purpose.

Abridged versions of both reports, R-1220-HEW (Abridged) and R-1420/1-HEW, are also available, summarizing the major findings.

ABSTRACT

More than 9 million mentally or physically handicapped children and youth in the United States aged 0 to 21 are impaired enough to need services not required by "normal" youth. The present report's earlier companion piece, R-1220-HEW, describes all major current federal and state programs for mentally and physically handicapped youth, details the nearly \$5 billion spent on them annually, and identifies major problems impeding the present service system. The present, and final, report evaluates current policies and suggests alternative future policies for improved delivery of services to the approximately 683,000 youth who are hearing or vision handicapped. Because current service problems and policies generally apply to all types of handicapped children, many of our recommendations, if adopted, would result in improved services for all types of physically and mentally handicapped children, as well as for those with sensory handicaps.

Currently, there are over 50 different major federal programs and hundreds of state and local programs, which together expend about \$420 million a year for service to hearing and vision handicapped youth. Without question, most of the programs are worthwhile; but the service system faces major problems, and with better organization and support it could do far better. Many youth are not receiving services, or are receiving the wrong or inadequate services. Extreme inequities prevail in the delivery of services; there are serious gaps in services offered; information is insufficient, control is inadequate, and most important, the resources devoted to these youth's needs are insufficient.

We interviewed 77 families with hearing and vision handicapped children, and they expressed deep appreciation for the services received, but fundamental dissatisfaction with the service system. They affirmed that failure to seek out children with handicapping conditions is a major problem; no one adequately knows what services are needed and available and where to get them locally; services located near the families' homes are often incomplete; and the quantity of available service is often not sufficient.

Any large-scale effort to improve services for these youth must begin with their basic service needs (which are a function of the youth's age, type and degree of actual or potential handicap, and several other factors): prevention of handicapping conditions, identification of handicapped youth, direction to the appropriate service providers, medical treatment, sensory aids, special education, counseling, special training, vocational training, job placement, recreation, social activity, transportation, personal care, income maintenance, training of personnel to supply the services, construction of service facilities, and research and development.

To aid our evaluation, we developed several models of government roles for providing services and similarly categorized functional mechanisms and rationales for governmental involvement in service delivery. We considered an array of modest and ambitious objectives, which ranged from limiting current government expenditures to developing the maximum potential of every handicapped person. Evaluation criteria used included measures of the individual's quality of life, future economic benefits, equity, and current resource consumption.

Our recommendations range from termination of some programs to consolidation and expansion of others, and from improvements in the management and structure of service programs to shifts in the mix of services provided. Chapter 2 of this report details our findings and recommendations and discusses priorities and

tradeoffs in meeting the service needs of handicapped youth. General strategic possibilities for service priorities are considered in four scenarios; each presents a group of recommendations fitted to a particular level of effort and objectives that official decisionmakers may deem desirable. Many other scenarios could be generated with the information presented in this report, but the four illustrated in Table A stress some major possibilities: limited or no change in the level of effort, but significant management improvement; minimal increase; modest increase in the current effort, tied to major long-term benefits; and substantial increase in effort to meet the full needs of handicapped youth.

The majority of our recommendations, if adopted, would yield benefits that exceed their costs even if the benefits are to be measured in sheer dollars-and-cents terms, and the benefits certainly exceed costs from the humanitarian viewpoint of the great enhancement in the quality of life of the handicapped. Our recommendations are summarized in Table A.

Table A
SUMMARY OF RECOMMENDATIONS BY DESIRED CHANGE IN LEVEL OF EFFORT

Service Need	Recommendations by Desired Change in Level of Effort			
	Slight or No Change	Minimal Increase	Modest Increase	Substantial Increase
Direction	Evaluate and pilot test Regional Direction Centers for Hearing and Vision Handicapped Youth	Create a national network of Regional Direction Centers		
Identification	Increase program evaluation and applications research to discover suitability for widespread implementation Require various types of service personnel to report handicaps	Improve and expand pre-school identification programs Implement screening programs to reach every young school age child		
Prevention	Coordinate preventive research and operational programs		Vigorously pursue modified rubella immunization program Cover prevention services (without deductible) under Medicaid and proposed National Health Insurance	
Medical treatment	Evaluate Maternal and Child Health Service programs; consolidate resources on a few programs, and terminate others Consider consolidation of Medicaid and Crippled Children's Service programs Improve Medicaid program operations Improve medical treatment data collection and usage Narrow the gap between research and medical applications		Increase resources available to Crippled Children's Service program in the short term Develop and implement a National Health Insurance program covering all handicapped youth, with special provisions for their needs	
Sensory aids	Require medical exam prior to receipt of certain sensory aids Narrow the gap between research and application of sensory aids		Assure that all sensorially handicapped youth receive needed sensory aids	
Special education	Improve evaluation and planning information		Implement preschool special education for all youth who are severely hearing handicapped	Increase the percentage of handicapped youth served; increase the number of special education teachers; increase the comprehensiveness of types of special education available in each geographic area
Vocational services	Establish Vocational Rehabilitation service priorities; adjust incentives and reporting Increase program evaluation to discover suitability for widespread implementation Coordinate VR, Voc. Educ., Spec. Ed., and State Employment Service Activities		Expand the Vocation Rehabilitation program Modify the State Employment Service Program to provide more trained specialists and lower caseloads	
Income maintenance	Conduct research and evaluation; improve information Provide direct cash transfers to needy families for coverage of normal daily living expenses; use other mechanisms to provide other services		Insure that all Aid to Families with Dependent Children (AFDC) child-recipients receive screening and treatment under Medicaid, and direction to other services	Either revise the extra personal income tax exemption program for the legally blind to include all severely handicapped persons, or restructure the entire program concept Transfer handicapped AFDC child-recipients to the Supplementary Security Income program
Multiservice	Maintain the current federal role in serving deaf-blind youth Create a strong and vital federal Office for the Handicapped to obtain information and plan, evaluate, and coordinate services	Adopt all "Slight or No Change" in desired level of effort recommendations in each service need area	Adopt all "Slight or No Change" and "Minimal Increase" in desired level of effort recommendations in each service need area	Adopt all "Slight or No Change," "Minimal Increase," and "Modest Increase" in desired level of effort recommendations in each service need area

ACKNOWLEDGMENTS

We would like to acknowledge the cooperation and assistance of many people and organizations. Foremost, and without whose initiative this study would not have been conducted, are L. E. Lynn, Jr., former Assistant Secretary for Planning and Evaluation of the U.S. Department of Health, Education and Welfare; E. W. Martin, Associate Commissioner of Education, Bureau of Education for the Handicapped; and P. M. Timpane, former Director for Education and Social Services in the Office of the Assistant Secretary for Planning and Evaluation. C. H. Rieder and S. H. Woolsey, as project monitors for HEW, offered valuable guidance and considerable assistance in obtaining federal data. R. B. Herman, former Program Planning Policy and Coordination Officer of BEH, contributed significantly to the early structuring of the research. In addition, we received excellent cooperation in our interviews with more than a hundred federal officials responsible for the many programs providing services for handicapped youth.

We are also very grateful for the cooperation, data, and suggestions for program improvement we received in our interviews with each agency serving handicapped youth in the states of Arkansas, California, Illinois, Massachusetts, and Wyoming. In addition, over 160 agencies in the remaining states each contributed significantly by completing our mail survey questionnaires.

Several dozen families with handicapped children, organizations representing the handicapped population, and private service agencies have contributed their experiences and views, thereby adding a vital component to this research.

Several Rand colleagues and consultants also provided valuable assistance. R. E. Levien was responsible for the initial discussions with DHEW and provided very useful guidance throughout. J. Pincus, the manager of Rand's Education and Human Resources program, oversaw and helped guide the progress of the research. D. de Ferranti, C. N. Johnson, K. Kellen, H. L. Moshin, and B. Rostker all made valuable contributions to the research on which this report is based. E. N. Bowers and M. Roach provided excellent secretarial assistance during the conduct of the research and the typing of the manuscript. W. Harriss edited and significantly improved the comprehensibility of this report. G. H. Fisher and P. Y. Hammond reviewed and made helpful comments concerning earlier drafts of this report.

We are grateful for their assistance.

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Part I

IMPROVING SERVICES TO HANDICAPPED CHILDREN: SUMMARY AND RECOMMENDATIONS

Part I describes the study and summarizes the findings and recommendations developed in detail in Parts II and III for improving services to handicapped children, with emphasis on hearing and vision impairments.

“The blessing is not in living, but in living well.”

Lucius Annaeus Seneca
Epistolae ad Lucilium, 63 A.D.

Chapter 1

DESCRIPTION OF THE STUDY

This is the second of two reports on the findings of The Rand Corporation's comprehensive cross-agency evaluation of federal and state programs for assistance to handicapped youth (see Preface).

Handicapped youth, as defined in this research, are youth from 0 to 21 years of age who are physically or mentally impaired to the degree that they need services not required by "normal" youth. The study deals with people who are generally called hearing or vision impaired, speech impaired, crippled or other health impaired, mentally retarded, emotionally disturbed, or learning disabled. It excludes youth whose problems are more attributable to social conditions than to physical or mental disabilities such as "disadvantaged" youth.

The problem is great: of the 83.8 million youth aged 0 to 21 in the United States in 1970, more than 9 million were handicapped.¹

SCOPE OF THE RESEARCH

Our first report dealt with federal and state programs that provide services to all types of mentally or physically handicapped youth. It described the programs and many of their problems, and covered the following topics:

- The handicapped youth population.
- The services needed by the population: prevention of handicapping conditions, identification of handicaps, direction to appropriate service providers, counseling, medical treatment, education, special training (e.g., mobility or speech), vocational training, job placement, sensory aids and other equipment, recreation and social activity, personal care, income maintenance, training of personnel to supply the services, construction of service facilities, and research.
- The programs that make up the current service system, meaning all those through which federal and state governments contribute to the provision of the above services to handicapped youth.²
- Information, within the limitations of available data, on the institutional structure, functional service delivery mechanisms, clientele, resources devoted to various classes of handicapped youth, and related problems.

The first report described the service system in its present or base-case form.

This second report focuses on changes in the present service system—alternative future policies for improving the delivery of services to handicapped youth. It covers the following topics:

¹ Appendix A of our first report, R-1220-HEW, discusses prevalence estimates and definitions of handicapping conditions.

² We use the term "program" in a generic sense to describe a set of interrelated activities with some common unifying concept such as delivery of a common service (e.g., a rubella vaccination program); administration by a separate bureaucratic entity (e.g., the Vocational Rehabilitation program); or possession of a common goal (e.g., a research program for preventing birth defects).

- The handicapped youth population, with emphasis on aurally and visually handicapped youth at HEW's request.³
- Services, including the same ones treated in the earlier report, provided by federal, state, local and private programs.
- Alternative future policies, presented for consideration by the federal government and others, to alleviate problems, to improve services to handicapped youth, and to improve the institutional structure and functioning of the service system.

The scope of this research project is necessarily large and comprehensive, because the service needs, programs, and problems of serving handicapped youth are also large and comprehensive. The literature in the field is also vast, but researchers in nearly every phase of the field run up against the same persistent problem we encountered: a serious lack of evaluation data upon which to base definitive analyses and recommendations. Guarded provisos and caveats are often called for. Because this is an overview study that must, like other studies, work with what data are available, it does not pretend to answer all questions, and cannot go into great depth; but it does bring together many scattered items of important information into one convenient source, and generates a good deal of new information and perspective.

RESEARCH APPROACH

We have taken a *policy-analytic, comprehensive view of the whole system serving handicapped youth* to assess the relationships of the system's constituent parts to its whole.⁴ Such a view is not commonly taken by any single government unit—the basic reason that HEW requested this research. Admittedly, because we have chosen to be comprehensive, we may very well err in reporting or failing to report important details about the system's various components. We are aware of the problem and have worked diligently to minimize it.

We have also taken a *comprehensive, target-population view of the service needs of handicapped youth* to assess the relationships among service needs and to assess how well the current and proposed service system policies are delivering and will deliver the mix of services needed. Again because such a view is not commonly taken by government units, it is often difficult to make informed tradeoffs among services.

In looking at the needs of handicapped youth, we found it essential to *disaggregate our analysis of the population by type and degree of handicap by age*, since both needs and accessibility to the service system depend strongly on those factors.

A series of questions that we posed and attempted to answer illustrate various facets of the research:

- What are the *service needs* of each major subpopulation of hearing and vision handicapped youth?
- What are the characteristics of the *current service programs* for meeting those needs?

³ HEW made the request for this initial study because these youth's handicaps are more readily identified and classified than others; their handicaps can severely affect every aspect of their lives; a wide range of services and programs of varying effectiveness have been developed to serve them; the data appear more readily available for these handicaps than for some others; and the program objectives, effectiveness, and benefits may be more easily assessed than those for other handicapping conditions such as emotional disturbance.

⁴ Various aspects of our approach are described in Chapters 1 and 11 of our first report, R-1220-HEW.

- What are the *problems* in the present mix of services delivered and in the present institutional structure of programs for meeting the needs?
- What are the *objectives* of various participants in the system?
- What *criteria* are useful in evaluating and comparing policy options?
- What *service policy options* exist for alleviating problems and improving services?
- What are the *implications, in terms of costs and effects*, of meeting individual service needs and adopting program changes?
- What *federal and other government roles* might be adopted in implementing promising service-policy options?

With the data at hand, we can answer these questions only partially. The data often occur in inappropriate formats, are unavailable, are unreliable, or are not easily analyzed with conventional data processing techniques. We discuss below the problems created by data deficiencies, and try scrupulously to identify assumptions, limitations, and the extent of data quality and reliability.

For an evaluation as complex as this, no single methodological technique will suffice; we use a *multimethod approach*, with the specific method used in any given case being dependent on one's question and the available data. The comprehensive, problem-centered approach we have taken is also beyond the skill and endurance of any one person—it calls for *interdisciplinary* research. Our group includes people trained in operations research, political science, business administration, economics, applied mathematics, and public administration. Consultative specialists, physicians primarily, have been called upon as needed.

INFORMATION SOURCES

To gain an overview of the system of government-provided services flowing to handicapped youth, it was necessary to collect and analyze a great deal of information. The service system we found was fragmented, which implied that information about it would also be fragmented and that great effort would be required to collect and synthesize the data into a coherent picture.

Our information came from six basic sources: a survey questionnaire mailed to several major service agencies in each state; interviews with officials in 60 federal and state agencies; federal and state reports and unpublished data on specific programs; consultation with professional service personnel; literature in the field; and an interview survey of handicapped service recipients.

THE HEARING AND VISION HANDICAPPED YOUTH POPULATION

The physical ability of youth aged 0 to 21 to see and hear varies on a continuum from zero to better than normal. The youth's *functional* capability to see and hear—that is, to *use* his physical ability—also varies on a continuum. Consequently, definitions of the hearing and vision handicapped youth population must be rather arbitrary. They are not consistent among service agencies, nor should they be, since the definitions should be based on need for the type of service being offered. Nonetheless, the situation can be confusing. If they formally define their client populations at all, the service agencies often do not use clearly stated or consistent definitions.

For our own research we broadly define sensorially handicapped youth to in-

clude those with significant hearing or vision impairments that result in significantly reduced functional capability and in the need for special services not required by "normal" youth. Because this study is concerned with the government's policy of providing services, "handicap" is defined in terms of the need for services.

We did not strive to find a "best" single definition of a handicapping condition, because we believe that a single definition of a handicap to be used for every type of service is inappropriate. Our objective in the following discussion is to note some of the more commonly used definitions.

First, handicapping conditions usually have multiple dimensions. For example, the usual definition for "legal blindness" is that corrected visual acuity is no better than 20/200 in the better eye, or the angle of vision subtended is no greater than 20°. This particular test, however, does not measure vision over all ranges of distance. Many legally blind people are able to see close-up objects such as small print, and hence are not really "blind" for many of the important functions of everyday life. From the standpoint of service policy, which this report deals with, the definition of handicaps for service eligibility ideally should be based on need or functional capability as well as ability to benefit from the service. A definition such as that for legal blindness gives some indication of who needs service, but is not refined enough to indicate the type of service required and does not include everyone who needs special service. Operationally, this means that a set of definitions is needed for each type of handicap, not a single definition. This is true even if one can describe functional capability in terms of degree of physical limitation.

Of the 83.8 million youth aged 0 to 21 in the United States in 1970, there were approximately 21 million youth who required eye care; 180,000 partially sighted but not totally blind youth whose measurable acuity in the better eye was 20/70 or less with correction (of whom about 32,000 were legally but not totally blind), and about 13,000 totally blind (absolutely blind or possessing only light-perception ability). We consider a youth to be visually handicapped and in need of at least some types of special services if he is unable to see well enough to read normal newsprint—a sensory deprivation generally considered to occur at an approximate acuity of 20/70 or less, which describes the state of about 193,000 youth.

We are not fully satisfied with the reliability of the estimates presented here, but we believe that they represent the correct order of magnitude regarding people who require at least some special services. These estimates are at least plausible and are based on widely used data (see Appendix A of Rand Report R-1220-HEW).

Hearing losses may be grouped into two broad categories: deafness, or sense of hearing that is nonfunctional for the ordinary purposes of life; and hard of hearing, or a sense of hearing that causes difficulty with such things as understanding speech, but which is at least partially functional. Another breakdown of hearing loss is based on the average decibels (dB, ISO standard) of sound loss in the 500 to 2000 Hertz range, which includes much of the speech range. The average uncorrected hearing loss in the better ear can be divided into four ranges with the associated functional interpretation:

- 41-55 dB: Frequent difficulty understanding normal speech
- 56-70 dB: Frequent difficulty understanding loud speech
- 71-90 dB: Understands only shouted or amplified speech
- 91+ dB: Usually cannot understand even amplified speech

A different type of hearing disorder, on which very few data are available, is one in which the level of sound heard may or may not be normal, but where there are dysacusic disturbances primarily symptomized by garbled hearing.

Of the 83.8 million youth aged 0 to 21 years in the United States in 1970,

approximately 8 million had some hearing impairment (about 15 dB or more); approximately 440,000 were hard of hearing (about 41 to 90 dB), and approximately 50,000 were profoundly deaf (about 91 dB or more). For our purposes, a youth is considered hearing handicapped and in need of at least some types of special services if he has frequent difficulty understanding speech, or worse. By this standard, there was a total of about 490,000 hard of hearing and profoundly deaf youth in 1970. We caution that children should not be termed hearing or vision handicapped simply on the basis of physical impairment, such as precisely 41 dB or more hearing loss, since many children with less loss, say 25 to 40 dB, may be functionally handicapped and in need of special services (e.g., a very young child with less than 41 dB of loss may have an education or language development problem).

Of the approximately 683,000 youth in the United States who have either a hearing or a vision handicap, some not reliably known fraction are multiply handicapped, i.e., are also retarded, emotionally disturbed, learning disabled, crippled or other health impaired, or have more than one sensory handicap. A very few thousand are both hearing and vision handicapped; while commonly labeled "deaf-blind" a great diversity of sensory ability exists in that small population, few of whom are both profoundly deaf and totally blind.

MAPPING THE SERVICE SYSTEM

The assortment of institutions providing services to the nation's handicapped young people is so large and complex in its interrelationships that even trying to describe that system is a formidable venture. To aid in understanding and analyzing the system, we have devised an intellectual "map" to help locate and describe various aspects of the service system. First, we defined general *models* of the various types of service agencies and institutions and their respective *roles*. Next, we described *functional mechanisms* by which those key institutions produce services. Then, *rationales*, both implicit and explicit, being advanced by various people to justify the selection of broad classes of functional activities constituting policies and programs, were postulated to provide a sense of why the service system functions as it does. Finally, key *policy processes* by which the system appears to operate and change are laid out by detailing a general sequence of events through which policies and programs are created, implemented, and eventually ended.

While not precise, this map gives an overview of the service system and was very valuable in structuring our analysis. Throughout this report we discuss various aspects of public and private institutional roles, functional mechanisms for service delivery, and rationales for the recommendations made; and these discussions are much more detailed, complex, and specialized than the general map presented in Chapter 3 of our earlier Rand Report R-1220-HEW.

OBJECTIVES

As we surveyed the myriad goals and objectives of the present system serving handicapped youth, we were struck by their multiplicity, their vagueness, the contradictions between operational and stated goals, and the idealistic and absolute nature of some of the stated goals that rendered them somewhat less than useful in the practical selection and operation of programs. (For a more detailed discussion of objectives, refer to Chapter 4 of R-1220-HEW, and to individual program descriptions in Chapters 5 through 10 of that report.)

Understanding a system's stated and unstated objectives is one key to improving performance. Conflict can arise between objectives of all key participants in the decision sequence just outlined, of participants involved in operating the system, and of the service recipients. For instance, a legislator's objectives may result in policies sharply at odds with the objectives of parents.

Consider the goals of *the affected population*. From discussions we have had with sensorially handicapped people, we surmise that if they were to set program and service goals, such goals would often be in the vein of "the greatest good for the greatest number" and would include concepts such as:

- Assurance that the needs of all handicapped persons for services such as housing, medical care, and education are adequately met; and
- Assurance that each handicapped person has the opportunity to develop to the maximum potential functional capability consistent with his physical or mental impairment.

In reality, these goals have been attainable only for selected individuals because serving all handicapped persons requires a financial commitment that our society in general has not been willing to make. Because of resource limitations, other less costly objectives must be considered. HEW's "nondependency" goal could be a less ambitious one, for example.

The goals of *society as a whole* are fundamentally a collective ethical matter and hence not easily determined. Certainly, society's goals share humanitarian aspects with the objectives of the handicapped population, and society shares resource constraints with those providing individual services and operating specific programs. But unique and conflicting aspects of the goals tend to predominate and make it nearly impossible to determine "society's" goals.

Tradeoffs of services across populations must be made, and the basis on which tradeoffs are made may take extreme forms:

- Restrict current public expenditures—which implies low emphasis on services, especially expensive services such as education.
- Minimize total expected public expenditures over the lifetime of the handicapped—which implies high emphasis on vocational rehabilitation and preventive services and considerably less emphasis on welfare.
- Emphasize services provided primarily to the severely handicapped and the poor—which implies a conscious discrimination against the mildly handicapped and the nonpoor.
- Emphasize services for the mildly handicapped when doing so achieves greater effectiveness per dollar expended—which implies discrimination of another extreme.
- Increase the number of people served for a given fixed budget to increase equity—which can imply that those having relatively greater needs may not be served, or a large number of people may be served at an ineffective level or quality.

Of course, the above are usually not objectives in themselves, but factors that may influence the objectives actually stated or used.

CRITERIA FOR MEASURING PERFORMANCE

Because fundamental contradictions are evident in some of the very global program objectives posited for helping the handicapped, the attempt to measure progress can be an uncertain enterprise.

Multiple measures and criteria are required for assessing system performance and measuring policy outcomes. Considering the variety of possible program effects, one must also use multiple criteria to evaluate policy alternatives, since the choices are so complex that it is both inappropriate and misleading to consolidate a set of criteria into one overall effectiveness measure. More important, we need basic information before we can start to use those multiple measures.

Because we are dealing with a variety of service objectives, it is useful to consider one set of simple dimensions along which several of the stated objectives might be measured, all the while taking the information deficiency into account. We have developed four dimensions and have created criteria to measure programs on each of them: (1) effects on the quality of life of the individual handicapped person, (2) future economic effects, (3) current resource consumption, and (4) equity (see Chapter 11 of R-1220-HEW). These dimensions permit one to make comparative judgments from several viewpoints without getting bogged down in arguments over which objective is "best." Besides, it is quite conceivable that several analysts using different objectives will arrive at much the same policy recommendation—the so-called "dominant choice."

At any rate, as can be seen by reading this report, it is unwise for anyone working with the severely deficient available data to expect great precision. Often, about all one can say with any confidence is that such-and-such a policy option would result in "major quality-of-life improvement" or "very low current cost relative to future economic benefits." Nonetheless, that may be enough. A sound policy choice can often be made if such general statements are known to be valid in the large.

FUTURE RESEARCH

The research approach and evaluation framework we have adopted can be useful in analyzing programs for many different populations besides sensorially handicapped youth. The research needs to be extended to include sensorially handicapped persons of all ages, and to include other types of handicaps, as called for in Sec. 405 of the Rehabilitation Act of 1973. In addition, the research approach appears to be generalizable to the comprehensive analysis of service programs for other target populations, such as the aged, American Indians, and migrant workers.

Later chapters of this report also point out many areas that badly need thorough research and evaluation.

STRUCTURE OF THIS REPORT

This report is divided into three parts. Part I describes the scope and approach of the research (Chapter 1) and summarizes our findings and recommendations for improving services to handicapped children, with emphasis on hearing and vision impairments (Chapter 2). Part II contains our detailed findings and recommendations for eight major types of service needs: direction (Chapter 3); identification (Chapter 4); medical treatment (Chapter 5); prevention (Chapter 6); sensory aids (Chapter 7); special education (Chapter 8); vocational services (Chapter 9); and income maintenance (Chapter 10). Finally, Part III (Chapter 11) summarizes the results of our survey of families with hearing and vision handicapped youth.

Chapter 2

SUMMARY AND RECOMMENDATIONS

SERVICE NEEDS OF HANDICAPPED CHILDREN

This chapter summarizes the findings of our cross-agency evaluation of government programs for handicapped youth, with emphasis on the estimated 50,000 profoundly deaf, 440,000 hard of hearing, 13,000 totally blind, and 180,000 partially sighted youth aged 0 to 21 in the United States in 1970. The hearing handicapped youth considered typically have an unaided sense of hearing that is sufficiently impaired to cause frequent difficulty in understanding normal speech; vision handicapped youth typically have corrected visual acuity in their better eye that is insufficient to enable them to read newsprint as normally sighted persons do. All of the approximately 683,000 sensorially impaired youth are impaired enough to need services not required by "normal" youth.

Recommendations for improving services to these youth were developed beginning with the following basic service needs; a particular youth may require anywhere from one to all of them, depending on his age, type and degree of handicap, etiology, previous services received, and other factors:

- Prevention of handicapping conditions
- Identification of youth who are handicapped
- Direction to appropriate providers of needed services
- Medical treatment to correct, alleviate, or stabilize the handicap
- Sensory aids
- Special assistance in obtaining an education
- Counseling of both the youth and his family
- Special training in skills such as mobility and speech
- Vocational training and job placement
- Recreation and social activity
- Transportation
- Personal care
- Income maintenance

This chapter summarizes government program expenditures for these service needs; discusses problems with those programs from the viewpoint of the service system as a whole and from the viewpoint of the handicapped population needing service; summarizes our findings and recommendations for each area of service need; and, in the last section, discusses priorities among our recommendations.

GOVERNMENT EXPENDITURES TO MEET SERVICE NEEDS

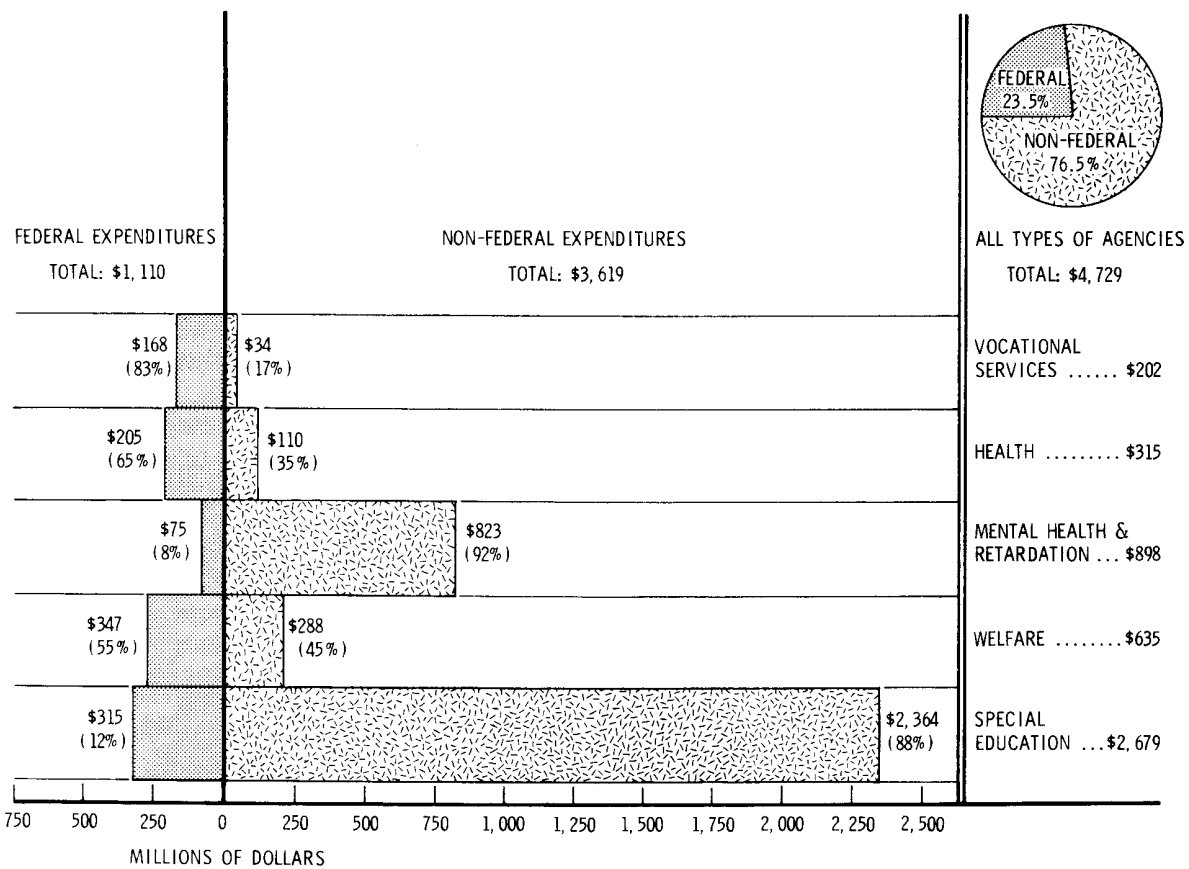
Government programs providing services to meet the needs of all types of physically and mentally handicapped youth are described in our earlier companion report.¹ In recent years all such programs expended nearly \$5 billion annually for

¹ James S. Kakalik, Garry D. Brewer, Laurence A. Dougharty, Patricia D. Fleischauer, and Samuel M. Genensky, *Services for Handicapped Youth: A Program Overview*, The Rand Corporation, R-1220-

services, as shown in Fig. 2.1. For ease of presentation, we have grouped the expenditures into areas by the five different types of agencies that administer them: health, welfare, education, vocational rehabilitation, and mental health and retardation. Each amount shown is for a single fiscal year—1970, 1971, or 1972, depending on the data available.

At the federal level alone there are over 50 different major programs providing services to handicapped youth. Most are within the Department of Health, Education and Welfare, but agencies as dissimilar as the Library of Congress and the Department of Defense also have such programs.

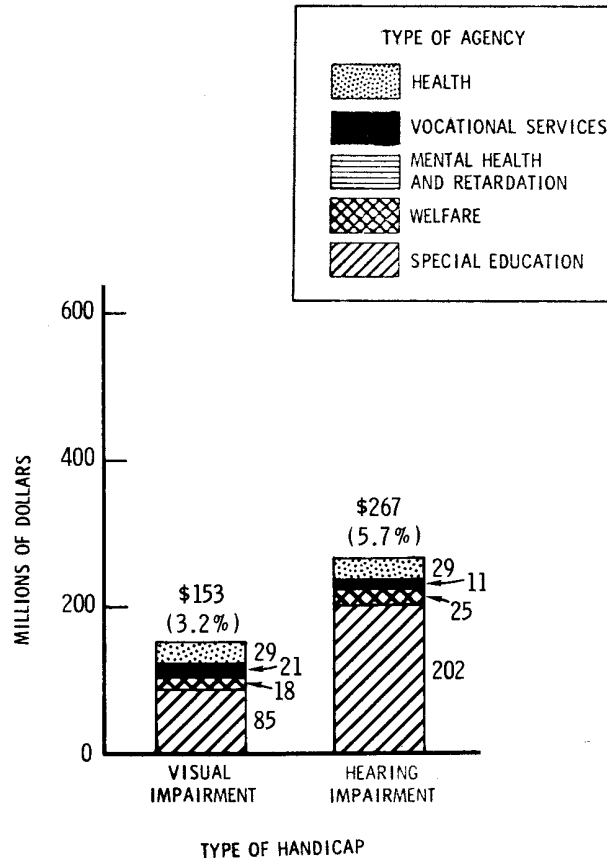
In recent years government programs expended approximately \$420 million annually for services to help meet the needs of hearing and vision handicapped youth, as shown in Fig. 2.2. Total budgets, however, do not give much insight into



SOURCE: Rand Report R-1220-HEW.

Fig. 2.1—Government expenditures for all handicapped youth

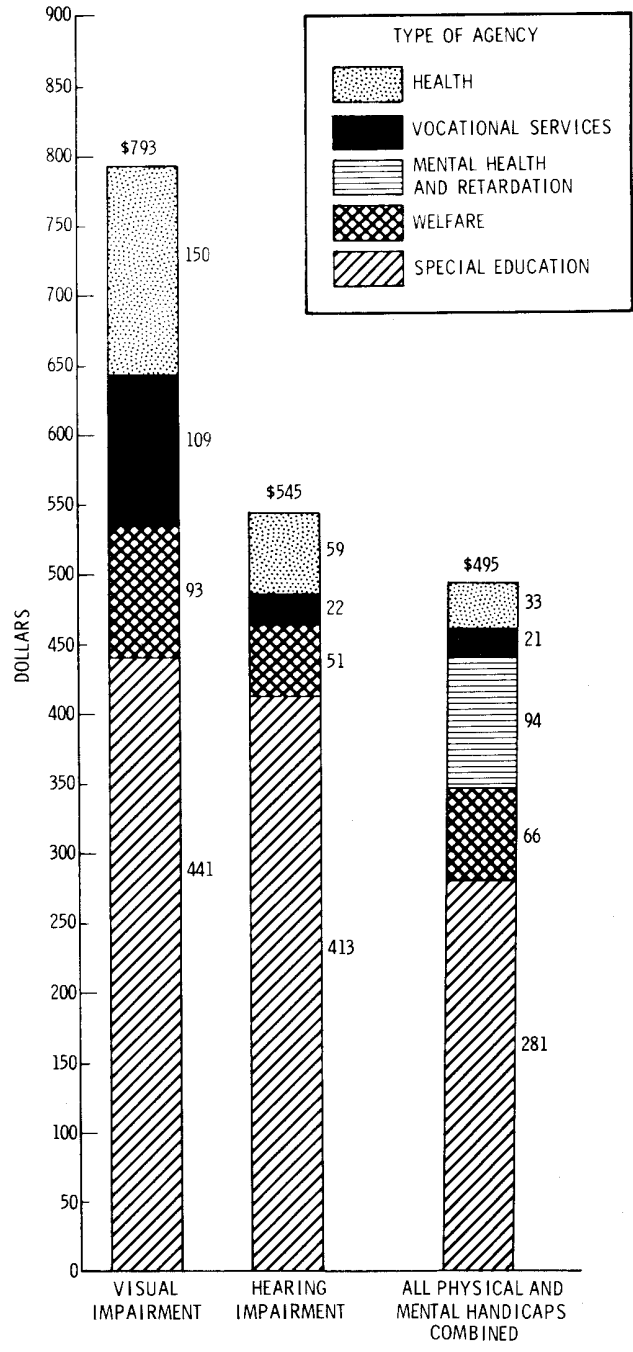
HEW, May 1973 (hereinafter cited as Rand Report R-1220-HEW). See also R-1220-HEW (Abridged), 22 pp.



SOURCE: Rand Report R-1220-HEW.

Fig. 2.2—Government expenditures for services to hearing and vision handicapped youth by type of agency

the services flowing to each youth. It is more illuminating to look at per capita expenditures. There being approximately 683,000 sensorially handicapped youth, the average annual government expenditure per capita is \$615. This does not mean that every sensorially handicapped youth receives \$615 worth of government service annually. Some obviously receive much more and many receive nothing. Figure 2.3 shows the distribution of this average cost among service agencies. Note that the expenditures in Fig. 2.3 are per handicapped youth, not per handicapped youth served. Funds expended per handicapped youth served are considerably higher, since many youth receive no service at all.



SOURCE: Rand Report R-1220-HEW.

Fig. 2.3—Annual government expenditures per hearing and vision handicapped youth by type of agency

PROBLEMS WITH THE PRESENT SERVICE SYSTEM

From the estimated \$4.7 billion expended by all levels of government annually, handicapped youth are receiving many needed and effective services. Humanitarian concerns are clearly evident in the expansion of programs and services in recent years. There is no question that the government programs serving handicapped youth have very beneficial effects; however, the service system faces major problems.

Despite the considerable sums of money expended by government and the private sector, the care and services provided to the nation's handicapped children are deficient in many important ways. Many children are still receiving no services, the wrong services, or inadequate services. The reason certainly is not a lack of programs. We have identified and discussed over fifty major programs in our survey of the current federal effort; there are hundreds when we add state, local, and private initiatives. Nor is the reason a lack of concern or effort on the part of service personnel, the vast majority of whom are dedicated people. Nor is it indifference in parents of the handicapped, many of whom make heroic efforts to secure needed services for their children. And no one can say that the quality of care that could be available is inferior, for the United States boasts some of the most advanced treatment methods and service techniques.

Perhaps it is easiest to blame inadequacy of funds, but that is too facile an answer. Insufficiency of resources is a major problem, but higher funding alone will not solve other basic problems that we find pervading nearly all aspects of the system: the complexity, lack of control, and disorganization of the system currently delivering services to handicapped youth defies efficient and effective operations; inequities and gaps in service delivery abound; and not enough information is available to manage the service system effectively and deliver the services needed.

To find out what the problems are, we interviewed officials responsible for major relevant federal programs and service agencies in five states, we tapped published material and agency data files, we solicited views on problems from every major state agency serving handicapped youth in all 50 states with a mail questionnaire, and we interviewed dozens of families with hearing and vision handicapped children. We also tried to view the system from a number of perspectives: that of the Office of the Secretary of Health, Education and Welfare, of the state and federal operating agencies, and of the handicapped person and his family. We also looked at the service system disaggregated by type of service need, agency, type of handicap, severity of handicap, age of the youth, geographic location, program, objectives, roles of the government, and the functional mechanism used to implement the program. Each view and disaggregation contributes different and important insights to the problems summarized below.

We summarize problems in meeting the needs for each type of service later in this chapter. In this section we survey five generic types of problems we found. (Details are provided throughout Rand Report R-1220-HEW, and throughout later chapters of this report.)

The problems described in this report and its companion piece can be grouped into five major classes, each of which is described below: (1) inequity, (2) gaps in services, (3) insufficient information, (4) inadequate or deficient control, and (5) insufficiency of resources. Obviously, these are not new types of problems; most of them are well known to professionals working with handicapped persons. Nor are these problems unique to this system, but they are critical to it and demand full examination. To begin this task, in our first report we compiled most of the available data to document their existence and extent; to complete it, we analyze those and other data in later chapters of this report to determine what might be done to resolve the problems.

Inequity

By any reasonable standard of fairness, a great deal of inequity prevails in the service system for handicapped youth. There is marked unevenness in the accessibility to, and the level of, services. Each program area has large and often extreme variation in per capita expenditures and services delivered across states and among handicaps. Eligibility rules vary markedly across the country. Within states, pre-school children and rural youth are short-changed by the service system.

One example is the favored income tax deduction treatment given the legally blind but not other severely handicapped persons. For another, consider the cross-state variations in the vocational rehabilitation (VR) program: in 1970 some states vocationally rehabilitated over 20 times as many totally blind youth on a per capita basis as other states did, and some states vocationally rehabilitated over 15 times as many hearing handicapped youth per capita. VR program expenditures per youth vocationally rehabilitated varied drastically across the states for youth with the same type and degree of handicap. Great disparities are also to be found between handicaps; for example, VR expenditures averaged \$6167 for the average totally blind youth, but only \$2068 for the average deaf youth unable to talk. The population of visually impaired youth received nearly twice the total VR expenditures that the hearing handicapped received; and despite the fact that a large fraction of the handicapped youth are unserved, 69 percent of the reported young visually *impaired* VR clients are *not handicapped* under the definition used in this report. Next, consider special education programs across the states: the estimated portion of visually handicapped youth aged 5 to 17 being served varies from less than 10 percent in two states to most of them in five other states; and for the hearing handicapped, the portion served varies from less than 10 percent in five states to most of them in four other states. For all sensorial handicaps, reported special education expenditures per youth served vary across the states from less than \$500 in several states to more than \$3000 in several others. In other words, whether a child receives special educational assistance, and the amount of that assistance, depend unmistakably and strongly on where his parents live. (To be fair, we should note that vocational rehabilitation and special education are cited here as examples, not because they are worse than other programs, but because more data are available on these two programs.)

Gaps in Services

Certain critical services are neglected and underdeveloped, particularly prevention, identification of those needing service, and direction or referral. It is especially significant that prevention should be neglected, because for numerous different types of hearing and vision disorders, high-quality preventive service is believed to completely forestall handicapping conditions in at least three-fourths of the cases of the particular type of disorder handled, and for some types of disorders, in at least 99 percent of the cases.

In many geographic areas, there are total gaps in available services—no special education for partially sighted youth, for example, or no high-school-level special education for deaf youth in the entire region. To get the educational services needed, the whole family has to move, or the handicapped child must be sent away from home. Even if a full range of services is available, however, the absence of an effective local direction service may cause gaps in the mix of needed services a child receives. Gaps may also result from the present institutional emphasis on single types of services. Many services, usually the “underdeveloped” ones, are not the prime responsibility of any one agency. Other gaps deprive particular age groups;

for example, many preschool deaf children are not receiving services important for their language development, and as a result may suffer permanent impairment of their language development. And gaps occur by state; for example, eligibility exclusions deny services to some types of children in one state, while a neighboring state imposes different exclusions in an identical type of program.

Insufficient Information

Management improvements in most program areas are hampered by the total absence or severe lack of reliable data that reflect the benefits and effectiveness of programs serving handicapped youth. Usually, even if an agency collects management data, the data are limited to resource inputs and not to service outputs. (There are, however, some notable exceptions—the vocational rehabilitation program is a rare and commendable example.) There is also a problem of low-quality or nonexistent planning and evaluation, stemming partially from the root problem of poor or nonexistent data. In most programs, methods to obtain high-quality data on program effects have not been established. In some programs, *no one* really knows who is doing what for whom or with what effect. Looking across all programs at the federal level, for example, no one agency knows for sure how many handicapped children there are, what they need, what services are available to meet those needs, or how effective those services are.

Insufficient knowledge of who the handicapped children are is also a problem. Agencies generally do not serve a significant portion of the population in need, are generally unable to say how many and who the unserved eligible handicapped youth are, and with notable exceptions, generally make no major effort to identify the population needing help. The result is that beneficial and effective services cannot be delivered.

Inadequate Control

The service system is varied, fragmented, uncoordinated, and not particularly responsive to an individual's total needs. The sheer number of institutions dispensing funds and services under many pieces of enabling legislation contributes to a situation in which no one person or group plans, monitors, or controls the handicapped service system in any comprehensive fashion. Policymaking, funding, and operating decisions are often made by entirely different groups of people, based in each case on an almost total lack of data about program effectiveness; consequently, accountability is generally very weak. There is no national policy for handicapped youth, to provide guidance for the many government programs.

Agencies responsible for a service sometimes do not even have control over the flow of funds for that service. For example, only about half of the federal funds for educational services for the handicapped flow through the U.S. Bureau of Education for the Handicapped. Relations among agencies at the management level are often perfunctory at best, and their responsibilities sometimes overlap considerably. For example, both the Crippled Children's Service and the Medicaid program fund medical services for financially needy handicapped youth, but generally do so without benefit of effective coordination in the states; and in practical terms, education projects for the handicapped supported under ESEA (Title III) and EHA (Part B) may be quite similar but are administered separately.

The handicapped suffer the ill effects of lack of control most immediately in their dealings with direction or referral services, which are highly underdeveloped. One result is that children are sometimes placed in expensive special education pro-

grams—by default, as it were—because they were not directed to medical treatment or fitted with sensory aids at an early enough age so they could function adequately in a normal school setting. Without direction, handicapped children and their families are left to their own devices to thread their way through a bewildering maze of agencies, services, and programs. The parents go from one place to another seeking help for their children, and often unknowingly pass by needed services that are actually available.

Control over service providers also varies markedly. For example, there are great differences in state laws requiring or not requiring medical and audiological examinations before children are fitted with hearing aids. The result is that handicapped youth sometimes receive hearing aids when surgery may be far more effective.

Insufficient Resources

A major fraction of all hearing and vision handicapped youth eligible for each type of needed service is not getting it. The lack of sufficient resources is the salient problem with today's handicapped youth service programs. Large unmet needs are common; for example, we estimate that in 1972-1973 only 21 percent of the hard of hearing, 72 percent of the deaf, and 55 percent of the visually impaired youth received *any* of the special educational assistance they needed. Inadequate resources (dollars, personnel, and facilities) was the problem most often cited by the authors of previous studies and reports, by special commissions, by agency officials we interviewed, and in the responses to our mail survey. Still, resources are not the only problem, and a great deal could be done to improve the services themselves, the institutional structure, the matching of services with clients needing them, and data on the service programs, without major increases in present funding levels.

Although the existing service system has many problems, many parts of it are excellent. The system as it is provides many needed services that greatly benefit the lives of handicapped children; but with better organization and support it could do far more.

SERVICE PROGRAMS FROM THE HANDICAPPED POPULATION'S VIEWPOINT

To evaluate current and future service policies requires information from *both* service providers and recipients. The handicapped population's perspective is absolutely necessary for a comprehensive study: the consumer's view of the world is fundamentally different from that of the service producer. Chapter 11 below reports in detail on our personal interviews with 77 families receiving aid from 665 different service providers. The families were selected about equally from (1) the diverse states of California, Massachusetts, and Wyoming; (2) four types of handicapped youth: totally blind, partially sighted, profoundly deaf, and hard of hearing; and (3) four age groups, 0 to 5, 6 to 12, 13 to 17, and 18 to 21 years. Although the survey is too small to use for other than heuristic purposes, it provided valuable insights into the needs and experiences of the handicapped, benefits of various services, and problems of the service system. The family survey should therefore be regarded as a supplement to and cross-check on other analyses performed in this study.

When asked to rank various service needs according to their importance, the families overwhelmingly rated education highest, with medical services and sensory aids close behind. They attached less importance to vocational training, financial

aid, transportation, job placement, counseling, and recreation. We did not ask families to rate prevention, identification, and direction on the same scale with the other services since these three services are fundamentally different from the others; but their great importance was repeatedly impressed upon us as the families told of their problems in first learning about their child's handicap and then finding appropriate services.

When asked if the services they received (from the 665 providers) had benefited their children, 62 percent of the respondents said they were very beneficial, 24 percent said they were somewhat beneficial, and 14 percent felt the services had yielded little or no benefit.

From the thoughtful and often well-informed opinions of the surveyed parents, a picture emerges of a service system that often surpasses the expectations of its users but still has some important shortcomings.

Our interviews led us to make the following major observations:

- In general, service recipients deeply appreciate the service system but are not fully satisfied with it;
- Initial identification of the handicapping condition is a major problem;
- Information about available services and direction to the appropriate mix of services is severely lacking;
- The range of services available within a reasonable distance of the families' homes is often very incomplete; and
- The quantity of service available is insufficient to meet the need.

Lack of Full Satisfaction with the Service System

Families were generally grateful for the available services, but they saw room for significant improvement, as detailed below. When asked to assess their experiences with all services and rate their satisfaction with the service system as a whole, 40 percent of the families said they were very satisfied, about half said they were satisfied but not completely, and 5 percent said they were definitely not satisfied. Parents of younger children and of less severely handicapped children were least likely to be satisfied. When asked about the individual services *used*, dissatisfaction was reported for 13 percent.

The Problem of Identification

Services obviously cannot be given to a handicapped child until the handicap has been identified, and at present identification is often haphazard, catch-as-catch-can. The parents in our survey reported that initial identification of the impairment was too frequently inaccurate (actual errors were reported by over 10 percent of the families we interviewed) or was not made early enough to help the child achieve as nearly normal development as possible.

Cases in point were profoundly deaf children, who particularly need service during the preschool, language development years. Several sets of parents of these children suspected a problem and consulted doctors. One child's pediatrician refused to believe the mother and would not test; four other children's doctors remarked variously that "nothing was seriously wrong," the child would "grow out of" the problem, it was "just a bad cold," or the child was "just fine." Another child was incorrectly labelled autistic, and another was treated by a psychologist for emotional disturbance for two years before his profound deafness was discovered.

Similar problems occur with the visually handicapped. One nearly blind child reached the first grade before her eyes were tested. Recounting the incident, the mother told us, "The kindergarten teacher just thought she was dumb." Still another partially sighted child was incorrectly called retarded.

While our sample is small, it is disturbing that identification can be so egregious.

Lack of Direction

Mentioned most frequently was the lack of *direction*—information about the mix of services needed and where to obtain them. Fully two-thirds of the families had difficulty finding appropriate services. Direction is a major problem because in most areas *no one* has all the information needed or the responsibility to coordinate help for families. The result is that there are gaps or delays in the services received, or inappropriate services are delivered.

Less than half the families were fully pleased with the amount and variety of services received. Initial contact with the service system was typically either a matter of fortunate chance or time-consuming, frustrating search by the parent; once initial contact was made, the search for service was a chain-like process of going from one agency to another, one at a time, rather than a process of sitting down and choosing among an array of alternatives. The parents' feelings about direction were nicely summarized by one of them: "*Someone* should do it!"

Gaps in Available Services

Fully 60 percent of the families reported that needed services were not available within a reasonable distance. For example, a high school program for the deaf may not exist locally or even regionally; local schools may offer services designed for blind youth but none for the more numerous partially sighted; several children had to go to residential schools so far away that their parents found it difficult even to visit them; 10 percent of the families moved to obtain appropriate educational services; several families could not obtain speech therapy anywhere near their homes; mobility training was seldom available for young children; and vocational training options were said to be very limited.

Insufficient Supply of Service

Even when a service is provided, the supply may be limited. Some parents had trouble getting their children into nearby school programs because the classes were full. And in one state where high-quality counseling and direction is available, the agency is said to be so understaffed it is unable to see each family more than once or twice a year. In total, only 40 percent were fully pleased with the overall *amount* of services received.

Asked whether they preferred private to governmental service sources, about half the respondents said they did not care. As one said, "As long as help is there, I don't care *where* it comes from." Of those expressing a preference, equal proportions said "yes" and "no" (about 23 percent in each group). However, only 5 percent of the sample thought that any service role now being undertaken by any government agency was inappropriate. Most parents could not conceive of an "inappropriate" role.

A government role to provide information about available services was enthusiastically endorsed by over three-quarters of the families surveyed.

SUMMARY AND RECOMMENDATIONS: INDIVIDUAL SERVICE NEEDS

We next consider the different service needs of individual handicapped youth in the following order: direction, identification, prevention, medical treatment, sensory aids, special education, counseling, special training, vocational services, transportation, recreation and social activity, personal care, and income maintenance. Also considered are research, service personnel training, and facilities construction as related to specific services. Current government programs to meet these needs are reviewed, problems are noted, recommendations for improvement are made, and possible federal roles in improving services are suggested. While all are important, we have concentrated our effort on services that the families we interviewed rated most important, such as prevention, education, medical treatment and sensory aids; on logically necessary prior services such as identification and direction; and on services where the government is heavily committed, such as vocational services and income maintenance. Following this discussion, we survey the entire system of government programs and establish priorities among the individual recommendations we make throughout the report. The emphasis throughout is on hearing and vision handicapped children, but because current service problems and policies generally apply to all types of handicapped children, many of our recommendations, if adopted, would result in improved services for all types of physically and mentally handicapped children.

Direction

Ill-coordinated, fragmented, and highly specialized programs tax a parent's ingenuity and perseverance as he searches through the official labyrinth to secure services for his child—an often repeated search, as it proves, because the child's needs change over time. Fully two-thirds of the parents surveyed had problems obtaining service, did not know where to turn for appropriate service, or worse, did not even know what questions to ask. The current service system is decidedly specialty-centered; it urgently needs to become child-centered. Agencies and professionals provide only one or a select few specialized services; and even assuming that each agency and professional performs well, each single service still meets only a fraction of the child's total requirements. Current specialized service professionals should not be blamed for the lack of coordination and direction, for they generally have not been given the specific responsibility and resources to provide the direction service. We need an institution to look at the child as a total human being.

Direction is an information-based service designed for the periodic and systematic matching of a child's needs with the proper mix of services to satisfy those needs as the child ages or improves in response to services and as the system's capacity to serve changes. At least, that is the ideal. Direction is critically important, but is at a primitive stage of development in the United States (see Chapter 3). It is not the main order of business for any of the federal or state agencies serving the handicapped. Even in public welfare agencies, where some direction is given, direction is not a central concern but occurs tangentially as a social caseworker might be required or inclined to assess a client's needs, search out the appropriate services, and then monitor the results. However, welfare is restricted to the poor; besides, most social workers have heavy caseloads, are not rewarded for "direction," and rarely have enough information to direct their young clients, even if they wanted to. The Maternal and Child Health Service also sponsors programs that do limited, noncomprehensive referral. Vocational Rehabilitation programs can provide a com-

prehensive range of services, but these do not reach young children and must be narrowly aimed at the achievement of a vocational objective. Schoolteachers and nurses sometimes help the parent find needed services; pediatricians sometimes help; and in some states, a "Commission for the Blind" agency provides limited direction service to a segment of the handicapped population.

In short, direction in this country is almost nonexistent, and where it does exist it is sporadic and uneven. And follow-up and redirection, implicit in the notion of "periodic and systematic matching," is even less developed. No one really does it, except for a few isolated and dedicated professionals who must make extraordinary and usually costly efforts to understand the overall system well enough to advise in areas outside their specialized competence. Comprehensive information about needed and available services is not generally available, and until it is, direction will remain an unnecessarily limited activity. Thus, the responsibility for matching the needs of the child with available services is a complex and demanding task left almost entirely to the parents, who are generally "ignorant" or poorly informed consumers. There are no generally available and reliable sources of local information to assist them. Without information and a systematic way of matching the child with the set of services he needs, the system often does not work very well. As families proceed from agency to agency, they are liable to be "captured" by one whose services appear adequate or at least better than no service at all. There is no way to find out how much misdirection is represented by capture, but its existence is unquestionable. It is also indisputable that a parent's random and undirected efforts may result in a less than optimal or comprehensive delivery of required services. The deficiency can be dealt with, and the cost of doing so is not prohibitive. In Chapter 3 we discuss a variety of potential solutions, and conclude that one very promising solution is to create Regional Direction Centers for sensorially handicapped children.

Effectively designed Regional Direction Centers would attempt to:

- Develop a one-stop, general information service to match the child's total needs with available services;
- Demand a multidisciplinary effort to balance and integrate the many specialized services needed by the child;
- Emphasize a dynamic, not static, orientation to account for changes in the child's needs over time;
- Maintain comprehensive service information on each handicapped youth;
- Foster client participation;
- Foster the humane personal dimension to create a comprehensive service program specific to each youth's particular needs;
- Serve *all* hearing and vision handicapped youth in the local region by stimulating an active outreach/identification and follow-up program;
- Concentrate on the practicality and feasibility of services and programs by stressing program service evaluation;
- Serve as a local spokesman for hearing and vision handicapped persons generally, and for individual clients particularly;
- Operate independently of the existing service control and incentive systems; and
- Coordinate programs to satisfy existing federal requirements for service integration.

To the extent that the above design characteristics are not implemented, one should expect problems of the following variety: for example, capture of the Regional Direction Center by the existing bureaucracy, overemphasis on certain services, or poor quality direction.

Direction Center personnel could provide outreach, diagnostic, planning, referral, and follow-up services themselves or through consultants as a needed supplement to traditional service providers—e.g., the providers of medical, special education, vocational rehabilitation, and welfare services. This mode of operation would not circumvent or duplicate the present service system, but make it more effective.

Many partial approximations to these design characteristics already exist. We have identified fourteen promising partial models in the United States and eight in Europe. The European direction services we examined are much more developed than those in the United States; but because of severe contextual differences, none of them can be adopted bodily in this country. Besides, we are aware of no model, either foreign or domestic, that is complete enough for such wholesale adoption. Several of the models embody highly promising features, however—in particular, certain aspects of the *conceptual approach* embodied in the proposed New York State “Child Advocacy System,” the *technical innovation* represented in Maryland’s “Data System for the Handicapped,” and several *institutional aspects* of California’s Regional Direction Centers for the Mentally Retarded. Judicious selection and combination of the better features of these and other examples would, in our opinion, do much to improve all services to handicapped children.

We present three specific recommendations to improve the provision of direction services to hearing and vision handicapped youth:

Undertake full-scale evaluations of the most promising existing partial models that provide direction service, to learn the strengths, weaknesses, and implications of each for an expanded, nationwide network of Regional Direction Centers for hearing and vision handicapped children.

Our preliminary estimates indicate a minimal national requirement for some 150 to 200 Regional Direction Centers (RDCs) for hearing and vision handicapped youth, assuming a load factor of about 4000 handicapped children for each center, or equivalently, an average catchment area of some 1.0 to 1.3 million total population for each. There should be at least one center to every state and Standard Metropolitan Statistical Area; the remainder should be located to minimize travel times in more remote, less densely populated areas.

The *modus operandi* of the RDC’s multidisciplinary staff, composed of persons specializing in existing disciplines as well as persons specializing in direction, would include initial screening, client intake, service plan formulation, plan execution, and periodic review and evaluation. Major review periods would occur at initial discovery of the handicap; at five years of age when the child is about to enter school; at nine years of age, when a detailed evaluation of the child’s school progress and prospects would be carried out; at fifteen years of age, when vocational services would become salient; and at twenty years of age—the “exit” age—to make a thorough assessment of the individual’s needs and point out available services for adults, such as vocational retraining. Minor review periods would occur when the parent raised a specific question between the major reviews, and the entire process would begin anew if a family moved to a new area.

The RDCs would be placed in a chain of command linking them directly to a State Advisory Council, which in turn would report directly to the governor and *not* to any existing service agency, such as health or education. To the greatest extent possible, this separate chain of command and compensation is needed to restructure incentives and to avoid “capture” by the existing service system. Finally, at the national level, we believe that a *strong* Office for the Handicapped within the Office of the Secretary of HEW would do much to focus attention on the needs of handicapped children, and could coordinate existing services and all State Advisory Council and RDC activities. Because such an Office for the Handicapped could

aggregate and summarize information generated by RDCs, it would be a vast improvement over the multitude of uncoordinated groups that currently compete for federal resources.

What would an RDC cost? Our initial planning estimate is that each center could be operated for about \$100 per year per hearing and vision handicapped child. If the child and his family received comprehensive direction service every four years on the average, then \$400 would be available—an adequate amount to provide at least minimum-quality direction, and one that may even be generous if volunteer help is used extensively as is proposed in the New York Child Advocacy model. Offsetting this cost would be the elimination of the need for other agencies to provide presently inefficient and partial direction. From the point of view of providing standardized, accurate, and rapidly accessible management information (currently nonexistent or rudimentary), the \$100 RDC expenditure would provide significant benefits. Humane, quality-of-life benefits gained by children and parents under any system are not calculable, but are very significant; a better system will enhance them. Benefits deriving from savings in services not needed by the youth later in life because of timely identification, evaluation of needs, and case management are also not readily calculable, but would be significant in the individual case and probably positive in the aggregate. The savings in rediagnosis and recertification realized by a simple transfer of client records from the center to various other servers would be considerable, but again not reliably calculable. The savings that would result from more effective matching of the needs of a handicapped population with the locally available services would also be positive. In brief, the cost per child for a direction service is not in itself excessively high, and the potential benefits and later savings from the service could be large, but how large cannot be accurately estimated.

Based on a rigorous evaluation of existing partial models, conduct a thorough implementation analysis prior to creating five to ten pilot RDC projects in locations throughout the country. Such pilot operations should themselves be carefully observed to insure that subsequent full-scale implementation can be carried out rapidly and with an absolute minimum of difficulty.

These pilot efforts would check out and permit improvement of initial estimates of cost, *modus operandi*, staff composition, and location, and would serve as definitive operating models upon which to base subsequent full-scale implementation. Since benefits from the evaluation and pilot project testing of RDCs would accrue nationwide, the federal government could assume responsibility for those activities.

Incorporate improvements in the Regional Direction Center design based on the pilot projects and expand the concept as rapidly as possible into a nationwide network of Regional Direction Centers for hearing and vision handicapped youth.

While we have stressed the benefits accruing to the families and children themselves, the present service system will also reap payoffs. Timely and efficient provision of appropriate services can eliminate duplication of effort and the need for other services later in life. Regional Direction Centers complement and are intended to make the present system more efficient; they operate within the context of the present service system without major disruption to the present structure. However, if the information-based direction service is effectively provided, then localized conflicts may arise as the unevenness in the quality of existing service programs becomes apparent. Coordinated regional, state, and federal involvement is needed to obtain maximum benefits from a nationwide network of these centers. And finally, when fully tested and developed for the relatively low-incidence population of sensorially handicapped children, the benefits of Regional Direction Centers could be extended to *all* handicapped youth and adults.

Identification

Identification is the recognition, correct assessment, and follow-up of both a child's abilities and disabilities (see Chapter 4). Three observations were corroborated again and again in our interviews with agencies and in our investigations of data on services provided to the handicapped: (1) agencies do not serve a significant portion of the population in need; (2) agencies generally do not even know approximately how many unserved people there are, much less who they are; and (3) very few agencies have effective outreach programs to identify the population in need. While we stress the importance of timely and accurate recognition of disabling conditions, specifically for the aurally and visually impaired, we want to stress equally that the identification process must not stop here. It is vital to link identification to a full, periodic, and humane assessment of the individual's needs because proper matching to available services can reduce or even eliminate handicapping effects.

Parents are usually the first to suspect hearing or vision impairment, and much identification is done informally, by schoolteachers and others not specially trained to recognize handicaps. Formal identification programs screen at least part of the child population in many states. They are far from universal, however, even for school-age children, and are often poorly implemented. Preschoolers usually get no screening at all.

Programs supported with funds from the U.S. Maternal and Child Health Service and Crippled Children's Service screened an estimated 10,000,000 children for vision impairment and 6,250,000 children for hearing impairment in 1973. (Because children in states with comprehensive screening programs usually are tested at more than one age, however, these figures do not represent children receiving their *first* screening.) While identification programs abound, coverage of the population is patchy. In a 1969 survey of Maternal and Child Health Service and Crippled Children's Service State Plans, 12 states reported having some type of general vision testing program, 20 performed some preschool vision testing, 19 had school vision testing, and 2 had glaucoma vision testing; 15 states reported some type of general hearing testing program, 11 had some infant hearing testing, 22 had some preschool hearing testing, and 23 had school hearing test programs. Some screening is also done under Medicaid, a state-operated but partially federally funded and regulated program, which requires early and periodic screening, diagnosis, and treatment of Medicaid-eligible children. It has been difficult to elicit compliance and full implementation of these provisions from the states, however. The present federal role with respect to identification programs is one of funding and research, not operation or strong control.

Without universal identification programs, no clear picture of the overall needs of the handicapped population can be drawn, and large gaps in service delivery cannot be filled. Without adequately trained, certified, and funded screening personnel, misidentification (errors of both omission and commission) occurs with distressing frequency. Lacking better informational connections between specialists providing identification and other services, follow-up and direction of people to an appropriate mix of services is often not done, or not done very well; neither is follow-up and adjustment of the total supply of services at the system level, to reflect changes in the number, kind, and distribution of the overall population.

As important as identification is, why is it so underdeveloped? Several plausible explanations are possible. Perhaps the most plausible—and the one most commonly heard—is that all available service resources are being used already, so it is pointless to go looking for more people. That argument may be answered in at least three

ways: an equity-related answer is that not all youth with the greatest need or the greatest ability to benefit are among those known to the service system; an adequacy-related answer is that if we were to identify more of those in need, the system might eventually respond with a more adequate level of resources; and an information-related answer is that even if the government chooses not to serve a handicapped person, that person might still be identified and armed with information about the exact mix of services he needs—knowledge that is helpful in seeking services that are not government supported.

We italicize below the improvements we believe are needed in the delivery of the identification service to hearing and vision handicapped youth.

Thoroughly research and evaluate various existing and proposed hearing and vision impairment identification programs and techniques, for both school-age and preschool children, to learn the operational details that contribute to effectiveness, and to assess their costs, benefits, and suitability for implementation throughout the country.

Existing research and evaluation work on identification is scarce, poorly coordinated, and insufficiently focused on implementation issues. Neonatal mass screening techniques for hearing and vision handicaps are not sufficiently reliable; they need further research and development. In the meantime, thorough evaluations of various preschool identification programs should be carried out by concentrating on programs for 2-to-3-year-old children. A remarkable variety of technologies is available in experimental form for preschool screening, but the connection is tenuous between experimental research and widespread application. Because a free flow between the two has national implications, the federal government has a legitimate stake in funding and conducting careful evaluations, studies of feasibility, and assessments of desirability of candidate preschool screening techniques; uncoordinated efforts by the states would probably entail unnecessary and expensive duplication of effort.

Improve preschool identification programs.

Finding severely hearing handicapped youth appears to be decidedly beneficial, especially if identification and subsequent services reduce the potentially permanent inhibition of language and speech development. Profoundly deaf and severely hard of hearing children need services the most before age 5, but they obviously are not going to get them if their handicap goes undetected. Visually handicapped and moderately hearing handicapped children also benefit from preschool identification, especially if their handicapping condition is treatable or correctable. Because there are critical unresolved questions about the potential benefits versus the actual costs of mass screening all preschoolers rather than all 5 year-olds, we do not recommend universal, mass, preschool screening for sensory impairment. High-risk registries appear desirable, however, especially for children at risk in the 0-to-5-year age group; such registries should be improved where they exist and created where they do not. High-risk children should be screened at birth, one to three times between birth and age 5, and again upon entering school. Persons in contact with preschool children—parents, day care personnel, nursery school teachers, well-baby clinic personnel, social workers, pediatricians, nurses—should be sensitized to the possible existence and impacts of hearing and vision impairment, and forearmed with knowledge of relatively simple tests for signs and symptoms. Existing institutional settings serving children aged 0 to 5 should be exploited as fully as possible to improve the chances of identifying the preschool handicapped. Federal money could be used for this, but because program operation requires coordination with state and local service providers, it is probably best accomplished at the state, intrastate, or regional levels.

Guaranteed-free checkups could help find handicapped preschoolers. If detailed evaluation confirms its apparent desirability, each child could be given free checkups at various ages, with an age-2 medical checkup to include careful screening for hearing and vision impairment and for other handicapping conditions. Reimbursement to pediatricians or other service personnel could be through the proposed National Health Insurance or some other health program, and would ensue upon their reporting the screening results to a health agency or other prescribed government agency. The recommended Regional Direction Centers would do much to coordinate and focus local attention on the general identification process and its follow-up. Direction is the next logical step in obtaining services after a handicapped child is identified.

Implement mass screening programs to detect aural and visual handicaps, reaching every young school-age child throughout the country, with program mechanisms to insure high-quality screening techniques, personnel, and follow-up.

Efforts should be expended to collect all standards currently in operation for all official hearing and vision screening programs throughout the country, so that these standards can be summarized, analyzed, and translated into a "model" code for hearing and vision screening, including procedural details required to fully describe all elements in the identification process. Such a model code should be periodically reevaluated as further research sheds light on means of improving the identification process. State certification and licensing boards are encouraged to consider requiring general, family, and pediatric physicians to demonstrate proficiency in hearing and vision screening and diagnostic procedures. We further encourage such boards to consider the need for improved and common standards for paraprofessionals and allied-skills professionals who conduct screening and diagnostic tests, and for test instruments and procedures. Follow-up to see that the identified child receives further diagnostic and other needed services is especially critical and should be a component of every screening program. Finally, every hearing and vision handicapped youth identified should be tested for the presence of other additional handicaps, and if found, directed to services appropriate to those other handicaps.

Carefully design and implement a program requiring physicians, teachers, and screening personnel to report all handicapping conditions to parents and to the State Departments of Public Health and Education.

We recognize that the possible clash of privacy and service norms is real in this case, but believe that careful design of the procedures insuring legal and moral safeguards is possible and desirable. (For a discussion of these issues, see a recent report by the HEW Secretary's Advisory Committee on Automated Personal Data Systems, *Records, Computers, and the Rights of Citizens*, July 1973.)

Prevention

Prevention is a neglected and seriously underused service. That fact is tragic, since a large fraction of the sensory handicaps in youth are preventable (see Chapter 6). That fraction may be as high as one-third or one-half, but given the poor state of the data, no one really knows for sure.

Remarkable numbers of diseases and disorders are capable of inflicting sensory handicaps that are preventable. Prevention can occur as the direct result of improved services, such as timely identification of the disorder and proper medical treatment; as the direct result of immunization efforts; or as the indirect result of improved prenatal care, family planning, genetic counseling, abortion, and other practices.

As contrasted with the nearly \$5 billion expended annually by all levels of

government for service to all types of handicapped children, we are able to identify only some \$50 million specifically targeted for prevention activities for children. In other words, about 1 percent is targeted for prevention and 99 percent for service *after* the child is handicapped. Roughly the same figures apply to the sensorially impaired subset of the overall handicapped population. If, for example, only one in ten of the existing handicaps in youth had been prevented, the total government service bill might have been reduced by about \$500 million per year for all handicapped youth, and about \$42 million for sensorially handicapped youth. With an 8 percent discount rate this represents, for *each* handicap prevented and for the present level of services, a total of over \$6000 in the cost of future government services over only the first 21 years the youth has the hearing or vision handicap. Without a doubt, the total value of a youth's enhanced quality of life due to freedom from sensorial handicaps is much greater than the absolute savings to the government. Although quality of life cannot be readily measured in dollar terms, let us assume, not unreasonably, that in this hypothetical example the quality-of-life benefits of not being handicapped are worth *at least ten times* the \$6000 reduced service cost. Then, on humanitarian quality-of-life grounds alone, this hypothetical prevention program would be justified if the cost were less than about \$60,000 per handicap prevented. In other words, in this example, the program would be justified on humanitarian grounds if costs averaged less than \$60 per youth and an average of only 1 youth in 1000 receiving the service had a handicap prevented as a result (or \$6 and 1 in 10,000, or \$600 and 1 in 100). Prevention makes good economic and humanitarian sense for many different types of handicapping disorders.

For numerous different types of hearing and vision disorders, high-quality preventive or medical treatment service is believed to forestall handicapping conditions in at least three-fourths of the cases of the particular type of disorder, and for some disorders, in at least 99 percent. Rubella, mumps, and measles are preventable by immunization. Ototoxic deafness resulting from the use of certain drugs is preventable. Otosclerosis can be surgically treated; and in fact, most conductive hearing loss can be alleviated with proper medical treatment, thus in a very real sense preventing a lifetime of handicap. Sensory handicapping resulting from Rh sensitivity is largely preventable. Any number of disorders, exemplified by various forms of otitis media, are liable to cause sensory deficits *if* they are improperly treated, left untreated, or treated tardily because of faulty identification and direction services. Amblyopia, cataracts, and glaucoma need early detection and medical treatment if handicapping is to be prevented, with the ideal early age ranging from a few months up to about age 2 (depending on the type of disorder). Retrolental fibroplasia (RLF) can be devastating, but it is generally known that the blindness it causes is due to an abnormally high blood oxygen level that may result from high concentrations of oxygen administered just after birth. Even at the current state of knowledge, a majority of those persons currently entering the population of those blinded by RLF should not be. Several disorders are detectable with *in utero* assessment techniques, even at the relatively underdeveloped state of the practice, but the degree of preventive potential depends upon the accessibility of an up-to-date identification and preventive care program, genetic counseling, and a parental choice whether or not to terminate the pregnancy when a major handicapping disorder is actually detected. Better prenatal care, to cite a more general prevention strategy, could reduce the chances of producing an abnormal baby by insuring early and periodic examination by a physician, curtailed use or avoidance of certain types of drugs, curtailed use of abdominal X-rays, avoidance of live virus vaccines, and proper nutrition.

If so many disorders are preventable, and demonstrably so, why do so many children continue to enter the handicapped population because of them? If so many

other disorders are suspected to cause handicaps, why is research on them so poorly orchestrated? A variety of explanations are possible. One may be undervaluation of investment in prevention. In being penny-wise by conserving today's prevention funds, present-oriented policymakers may be pound-foolish with respect to the future, considering the high human and economic costs of the handicapped person over the years. Underinvestment in prevention services may also occur because those who currently administer prevention programs—usually health agencies or personnel—do not reap the future savings in such services as special education, vocational services, and welfare. Other reasons are that it is hard to adduce compelling arguments for prevention of some disorders, given the current state of basic information; the fact that no one government agency is responsible for prevention in a direct and comprehensive way; and the insufficient attention devoted to applying research findings to preventive operations, and disseminating those findings to practicing physicians—a major source of prevention through medical treatment.

A single federal agency should be given prime responsibility and authority for prevention as a service. Studies should be conducted to collect much better information on prevention and to evaluate alternative prevention strategies for specific disorders so that more informed policies are possible.

Presently, federal prevention research and operational programs provide, at best, spotty coverage of the population and are scattered throughout various agencies. No single agency is primarily responsible for looking at prevention as a service, and hence making the tradeoffs between current prevention costs and future quality-of-life and service costs and other disbenefits resulting from inadequate prevention. At present, furthermore, few institutional mechanisms translate research findings into applied methods to prevent handicapping.

The proposed Office for the Handicapped, if sufficiently well staffed and given sufficient authority, could orchestrate federal prevention efforts. It would be desirable to rationalize research expenditures based on the needs of the population (particularly as they change) and to exploit research findings with evaluations and demonstrations, if called for; and basic benefit-cost analyses are needed to inform future debates about resources for research versus treatment, or prevention versus service after handicapping. The present lack of information and evaluation of prevention activities is extreme. At the local level, the Regional Direction Centers could be given responsibility for coordinating prevention efforts.

Revise and strengthen the rubella vaccination program, and provide funding for an open-ended time period.

The messages here are very clear: rubella can be prevented; many youth are not immunized; rubella-caused handicaps are prevalent, especially in youth whose mothers contracted the disease in the first trimester of pregnancy; and prevention is decidedly cost-effective just in terms of reduced future service costs, not to mention the extremely important effects of not being handicapped on the person's quality of life. We calculate that the increased special education costs due to the 1963-1965 rubella epidemic alone will exceed \$202 million. We recommend mandating rubella vaccination for all prepubescent females through a school-based program conducted under auspices of the National Center for Disease Control; creating a model code for state marriage license serologic screening practices with the objective of including an additional test for the presence of rubella antibodies; and making appeals through the mass media and professional medical publications to encourage all child-bearing females to obtain such tests from their private physicians.

Without deductibles, fully cover high-quality prenatal care, routine immunization services for children, eye and ear examinations for youth up to age 21, and

preventive medical treatment, in Medicaid and in any National Health Insurance program that may be implemented.

Adoption of this recommendation, and those made elsewhere in this report for early identification, direction, and medical treatment, is perhaps the best means of preventing handicaps.

Medical Services

There is a major need for high-quality medical care administered at the earliest possible time in an afflicted person's life, since a significant number of potentially handicapping disorders can be prevented, stabilized, reduced, or eliminated altogether with skilled medical treatment. For example, many, if not most, external ear, eardrum, and middle ear disorders are treatable with a very high likelihood of success in correcting or avoiding a handicapping condition.

Medical treatment available to hearing and vision handicapped children is discussed in detail in Chapter 5, to provide a summary of available prevalence data (disaggregated where feasible by age and etiology), to characterize most of the commonly encountered disorders and their various treatment methods and costs, and to provide some general idea of the likelihoods of outcomes of treatment and prevention efforts.²

Good medical treatment is available, but many handicapped children are not receiving it. Lacking early identification, accurate diagnosis, and timely direction, the best medical treatment in the world often is practically and tragically irrelevant.

Many disorders that cause hearing and vision handicaps, even the more exotic ones that require highly specialized attention, can be treated at remarkably low cost relative to the expected lifetime costs of services to a handicapped person. On cost grounds alone, a convincing argument often can be made that the best medical treatment available represents an investment in reduced claims on society and the public treasury. In any event, add to the cost argument even elementary humanitarian concerns, and the basic case becomes undeniable.

To provide good-quality medical care to our nation's handicapped youth is not a "blue sky" objective. The tradeoff, in rational terms, is between lifetime quality-of-life and economic costs for a permanent disability and possibly one-time and relatively limited costs for proper medical treatment, with all that might entail for the aggregate reduction in the number and severity of handicaps in the population.

In addition to considering medical treatment services for hearing and vision handicapped youth, we have also assessed federally supported medical programs for handicapped children in general (see Chapter 5 below and Chapter 8 of Rand Report R-1220-HEW).

Federally supported health-service programs are estimated to have helped at least one million handicapped children in FY 1971. (The reported figure was over one and one-half million, but it includes some unknown amount of double counting

² Hearing disorders discussed include: serous otitis media, acute and chronic otitis media and mastoiditis, otitis externa, perforation of the eardrum, bullous myringitis, labyrinthitis, mumps, measles, and other infectious diseases, nerve tumors, cholesteatoma, foreign bodies lodged in the ear, cerumen, trauma to the Organ of Corti, drug effects on the auditory nerve, hearing loss due to noise, maternal rubella, congenital malformations of the Organ of Corti, erythroblastosis fetalis, stenosis and atresia of the external auditory canal, congenital malformation of the eardrum, and otosclerosis.

Vision disorders discussed include: strabismus, amblyopia, retrolental fibroplasia, nystagmus, myopia, astigmatism, cataract, toxoplasmosis, coloboma, aniridia, albinism, macular degeneration, retinitis pigmentosa, retinoblastoma, hypermetropia, dislocated lens, glaucoma, optic nerve atrophy, corneal ulcers and scars, keratitis, burns, fracture of the orbit, contusions of the globe (including hyphema), foreign bodies, choroiditis, retinitis, iritis, and cyclitis.

because of children receiving services from more than one program.) Total federal and state expenditures in this area were at least \$315 million in FY 1971, of which the federal share was \$205 million and the state share was \$110 million. Of that total, our best estimate is that the federal and state expenditures for health services to aurally and visually impaired youth were \$28 million and \$29 million, respectively. State and local expenditures not known or not reported to the federal government would raise the total even further. The largest single federally supported program in this area is Medicaid, which serves youth from financially needy families and which was estimated to have expenditures of some \$186 million in FY 1971 for all handicapped youth. The second-largest program is the Crippled Children's Service (CCS), which provides medical services to financially needy children having nearly all types of handicapping conditions and which had expenditures totalling at least \$88 million in FY 1971. These and many other federally supported health programs, mainly within the Maternal and Child Health Service (MCHS), are discussed.

Medical programs having large beneficial effects on the lives of all handicapped children are summarized in this report as well as they can be, given the dearth of programmatic information and data reflecting the status and needs of the handicapped subset of the population. While there are three main federally supported medical programs serving handicapped youth—Medicaid, MCHS, and CCS—many more are located in rehabilitation programs, in Department of Defense programs for military dependents, in the Veterans' Administration, in NIMH, in Project Headstart, and so forth.

We have several program recommendations for medical services.

We recommend that the Office of the Secretary of HEW conduct, as soon as possible, a full scale evaluation of all Maternal and Child Health Service (MCHS) supported programs with the end in view of concentrating future resources on the critical needs and most effective programs. The remaining programs would be candidates for termination. Research studies on specific disorders should be transferred to the cognizant National Institute of Health.

It is practically impossible to measure and summarize the benefits of MCHS programs in any meaningful fashion because of the diversity of programs within the MCHS's general purview, the lack of data, and the insufficient attention that has been paid to program evaluation over the years. MCHS has been responsible for the creation of many demonstration efforts at the state level that have been innovative, stimulative of better general care for children, and in a real sense worthwhile. However, the numerous programs so dilute the limited available resources that they often end up without enough leverage to solve some manageable subset of maternal and child health problems.

Pending resolution of difficulties that have been experienced with the present Medicaid program, and pending the adoption of a National Health Insurance or some other program designed to make good-quality comprehensive medical care available to all youth, we recommend that the Crippled Children's Service program be retained and expanded.

CCS provides medical and other health services to all types of handicapped youth in financially needy families, and the determination of which handicapped persons to serve and of financial need is left to state officials. Some state programs have achieved remarkable success in creating and implementing the highest standards of medical care for handicapped children. A number of reasons have been suggested for this success, including: having medical specialists integral in program administration, the maintenance of high standards of treatment quality, the evolutionary nature of the programs, and favorable physician acceptance of medically

based programs as compared with the welfare-based (and often welfare agency administered) Medicaid program. However, unlike the Medicaid program, CCS is closed-ended, with a fixed annual budget inadequate to meet the population's need. Categorical coverage, as determined locally according to available resources and local precedence given to certain classes of impairments, contributes to inequitable coverage from state to state and within the same state at different phases of the fiscal year. Nonetheless, this program should be retained in the short term since it is a major source of much needed medical treatment for handicapped youth.

In the short run, pending the adoption of National Health Insurance or some other program designed to make quality comprehensive medical care available to all youth, we recommend that consideration be given to integration of the CCS and Medicaid programs in the states.

The desirable comprehensive and financially open-ended nature of the Medicaid program could benefit from some of the apparently better program administration features of CCS, and both programs currently provide medical treatment for all types of handicapped youth in financially needy families. A thorough evaluation of methods and effects of integration should precede implementation.

Significantly improved management procedures should be implemented to yield much better Medicaid program management information; to reduce delays; to improve the equity of eligibility standards; to insure that mandatory provisions are implemented (e.g., screening); and to permit revision of medical payment schedules to reflect the realities of the medical marketplace. Coverage of all Supplementary Security Income recipients should be assured.

The nature and quality of the various state programs is highly variable, as well as can be determined from the spotty evaluations that have been done. Attempts are being made to improve management information, but current deficiencies are very large. Reportedly, as with CCS, the payment schedule is often significantly lower than private rates. This disparity, coupled with red tape and slow payments, has apparently led more than a few physicians to avoid Medicaid patients. Program emphasis has been concentrated on treatment, but since 1967 there have been provisions for mandatory early and periodic screening, diagnosis, and treatment of Medicaid-eligible children. Compliance and full implementation of these provisions have been hard to attain from the states.

The Department of Health, Education and Welfare (the proposed Office for the Handicapped or the Office of the Assistant Secretary for Planning and Evaluation) should institute a thorough and continuing review of current procedures for collecting and using data on medical and other services and on resources expended; this would be an important first step toward improving services to the handicapped generally, and toward improving the availability and use of information on all types of services.

Data on the medical and other needs of the handicapped population, and on services delivered, are extremely deficient in quantity, form, and reliability. Improved information would furnish a more sound basis for legislative and executive agency actions that strongly affect both government expenditures and the lives of the handicapped population. A further remedial step would be to include a segment of questions on medical and other services to the handicapped in the 1980 Census of the Population.

With an improved research management information system, NIH or the proposed Office for the Handicapped could lead catalytic activities to diffuse improved medical treatment methods by identifying promising research findings and then stimulating the development work required to make these research findings of general, practical use.

No one at the federal level has prime responsibility to insure that research results are developed and disseminated in the recommended fashion. The result is that the process, if it occurs at all, is protracted unnecessarily. In-service training of specialists who are not at the forefront of medical knowledge is presently no one's prime responsibility. Treatment methods vary from the most highly specialized practices to general practices found throughout the country. The Department of Health, Education and Welfare could accept responsibility, in the form of an emphasized catalytic role, to sense improvements in medical treatment methods for the handicapped population and help insure their diffusion.

In the longer term we endorse the concept of National Health Insurance (NHI), provided that it is properly implemented and that it includes provisions leading to the availability of medical services to all handicapped youth in need, and provisions for meeting the special needs of handicapped persons.

HEW, in particular the Office of the Secretary or the proposed Office for the Handicapped, might review and react to *all* NHI proposals to assess their likely effects on the lives of the handicapped. Through adoption of NHI the government can, in effect, make sure an insurance policy is available to parents so that handicapped children do not become an economic catastrophe for them, and so that handicapped children can receive the medical services they need. In the longer run, NHI could greatly reduce the current reliance of the handicapped on noncomprehensive medical programs that do not serve significant proportions of those eligible and in need (see Chapter 5 of this report, and Chapter 8 of Rand Report R-1220-HEW). However, the legitimate specialized needs of the handicapped can best be served if NHI includes certain features. For example, any NHI plan finally made into law should explicitly provide for continuity of treatment during the transition from the current to the new medical service system, and for prevention, screening, extended medical treatment, medically related sensory aids and other equipment, coverage of preexisting conditions, extraordinary transportation costs related to medical care, and catastrophic contingencies. Many of these provisions should not be subjected to a "deductible" so as not to discourage receipt of needed services. Furthermore, those provisions should pertain to all handicapped youth up to age 21 *generally*, not solely to hearing and vision handicapped youth.

For a number of practical reasons, it would be surprising if a viable NHI program were operational within the next two years. Consequently, the short-term recommendations presented above for improving MCHS, CCS, and Medicaid programs should be regarded seriously.

Our previous recommendations for the direction and identification services should be adopted as expeditiously as possible.

Identification and direction are critical, missing elements in the delivery of medical treatment; any improvement in these two neglected services must reduce the total handicapped population, and alleviate handicaps within that population, because of the improved preventive and remedial services received. The finest specialized medical care in the world can be rendered useless if local identification and diagnosis services are inadequate.

Sensory Aids

Sensory aids and related equipment currently in use include corrective lenses and other optical vision enhancement devices, closed-circuit television systems, talking books, tape recorders, large-print and braille reading material, canes, guide dogs, hearing aids, captioned films, and speech training aids. Many other promising devices intended to aid in reading, writing, mobility, speech training, and speech

perception either are not yet fully developed or are not yet widely used. They include such devices as hearing aids that not only amplify but also modify the frequencies at which aural information is presented, captioned TV, and devices for converting visual information to tactile or aural information, and for converting aural to tactile or visual information.

Chapter 7 below reports on the population needing sensory aids and on the cost and effectiveness of current and potential aids, reviews the multitude of government programs concerned with these aids, discusses some foreign countries' programs, and presents recommendations for program improvement. Our companion report, R-1220-HEW, provides more detailed information on government programs involved with sensory aids.

Nearly *all* hearing and vision handicapped youth need and can benefit from some type of sensory aid, but a majority do not have the aids they need. For example, the device most often used is the hearing aid, yet only about one-third to one-half of the hearing handicapped youth have hearing aids, and the use of such aids is a function of family income.

Current annual expenditures on sensory aids for handicapped youth are impossible to determine accurately because they are generally part of a larger budget in one of the many programs concerned with such devices. Working from known expenditures for aids, however, we estimate that the total is at least \$40 million a year in public and private expenditures, and is probably about \$50 million. It would cost at least another \$50 million a year to provide aids to all youth that need them.

Nearly all public agencies serving handicapped youth expend funds for sensory aids, but no agency has major responsibility for perfecting and disseminating these aids. Some school systems purchase classroom sensory aids, and sometimes even personal aids. HEW's Media Services and Captioned Films program develops and supplies sensory aid materials. Federal funds support the American Printing House for the Blind. Vocational Rehabilitation agencies purchase hearing aids, corrective lenses, and other reading, writing, and mobility aids for the visually handicapped. States can purchase sensory aids under the Medicaid and Crippled Children's Service programs, and welfare funds are sometimes used for this purpose. The Library of Congress supplies talking books and braille materials through a system of regional libraries in every state. The National Institutes of Health, the Social and Rehabilitation Service, the Veteran's Administration, the National Academy of Engineering, the National Academy of Science, the National Science Foundation, and the National Bureau of Standards are all partially concerned with the development of sensory aids.

The funding of sensory aids is partly governmental, through a multitude of programs, and partly private. The actual dispensing of the two commonest aids—corrective lenses and hearing aids—is typically private, but is done under governmental regulation in many states.

Several problems afflict current programs concerned with sensory aids. The programs are numerous, fractionated, and unorganized. Too few youths needing sensory aids have them, and there is no mechanism for insuring that children who need sensory aids receive them. Those that do have sensory aids often need, but do not adequately receive, training in the use and routine maintenance of the aid. If one believes that access to an aid should be a function of the child's need, not family income, then there are inequities in distribution. Considerable progress has been made in creating new aids, but many of these are not properly tested and guided through the many steps needed to convert a promising prototype device into a rationally designed production model; and institutional mechanisms for assuring that production models are widely distributed among the handicapped consumers need much improvement.

Sensory aids were rated in the top three most important services by the families we interviewed. Hearing aids and corrective lenses were the aids most often mentioned as being valuable; however, these aids may have been singled out by the families because they are the types most likely to be needed and are also the best known aids.

Our recommendations for improving the quality, quantity, and distribution of sensory aids concern the sensory aids directly and also concern the related medical services needed to make a sensory aids program more effective or to eliminate the need for the sensory aid altogether in individual cases.

All hearing and vision handicapped youth who can benefit from sensory aids should be assured of having them.

The judicious choice of a sensory aid can make the youth less functionally handicapped, lessen his need for other special services such as education in a special classroom, and improve the effectiveness of other services such as education and job training. Sensory aids appear to be relatively cost-effective and to improve the youth's quality of life significantly, especially the two types of aids most often needed—corrective lenses and hearing aids. Depending upon which of the many different types of sensory aids is needed, the youth or his parents may also need to be trained to use and maintain the aid.

Many children do not receive sensory aids because their handicap is not identified. An identification program would be particularly helpful to preschool hearing handicapped youth, who should be fitted with hearing aids as early as possible to facilitate language development.

With proper direction, parents and teachers would receive important information about the value of various types of sensory aids available, their appropriateness for the child, and where to obtain them. Direction would also help to coordinate the presently fragmented delivery system. In addition to creating and expanding the government's role in identification and direction, several specific options exist: screening for need, and payment for certain sensory aids, could be made a fully covered expense without a deductible for youth up to age 18 or 21 under proposed National Health Insurance plans; as in certain foreign countries, families with sensorially handicapped youth could receive a voucher periodically to pay for sensory aids, with the amount and timing of the voucher dependent upon the type and degree of sensory impairment (all families might be included, or the program might be limited to families receiving income maintenance); and schools could provide free sensory aids to youth from financially needy families.

Coordinated and intensified effort is needed in support of research and development programs aimed at designing and testing new aids for the handicapped, and to convert promising prototype devices into fully human-engineered production instruments.

Some new devices currently undergoing research and development show promise of giving the visually handicapped ready access to normal printed material and of significantly improving their mobility. Others promise to give the hearing handicapped a significantly improved capability to perceive speech. Considering both the current state of the art of sensory aids and the levels of research and development expenditures in relation to the sizes and needs of the two populations, greater emphasis on sensory aids for the hearing handicapped is called for, and increased expenditures for research on aids for both the hearing and the vision handicapped would be justified. Because such research and development benefits the entire nation, the federal government is a legitimate focal point for these efforts.

Since an impairment can often be stabilized, alleviated, or eliminated medically or surgically, a medical specialist should examine the child before certain sensory aids are dispensed.

A hearing impaired person, for example, may have a very severe unaided and uncorrected hearing loss due to a correctable malfunction or degeneration of the eardrum or one or more of the small bones in the middle ear. Medical or surgical intervention may enable him to hear so well that he has no need for a hearing aid and has little or no difficulty understanding normal speech. Some states already require a medical examination before certain devices such as hearing aids are dispensed, and also regulate suppliers; these requirements could be standardized and extended. The proposed National Health Insurance payments for corrective lenses and hearing aids could be conditioned upon a prior medical examination by a specialist; and the quality of certain sensory aids could be regulated, as medically related devices, by a federal agency.

Special Education

We estimate that about 379,000 hearing handicapped and 123,000 visually handicapped youth need some special assistance in obtaining an education, ranging from the provision of sensory aids only to education in a residential institution. Basically, these are youth who cannot read normal newsprint even with corrective lenses, or who have frequent difficulty understanding normal speech. At present, only about 83,000 hearing handicapped and 28,000 vision handicapped youth are served by special education programs. The structure of the education program emphasizes service to the more severely handicapped—the totally blind and the profoundly deaf. The public schools are the primary agency for delivering service, and the education program for hearing and vision handicapped youth is directed predominantly at youth aged 5 to 17 years. Current state and local expenditures for special education are \$146 million annually for hearing handicapped and \$66 million for vision handicapped youth. The corresponding federal expenditures are \$57 million and \$20 million (a complete discussion is contained in Chapter 8 and in R-1220-HEW, Chapter 6).

The trend in service has changed from serving only a few youth, mainly in residential schools, toward serving many with a system that provides a variety of resources for special education, such as special day classes, itinerant special education teachers, and resource rooms to supplement the services provided in a normal classroom.

The federal program for aid in educating handicapped children has not grown within the framework of a comprehensive plan; like many other federal program areas, it is a patchwork of loosely related activities. For example, two programs (Elementary and Secondary Education Act—Title III, and Education of the Handicapped Act—Part B) in practice may fund almost identical activities, yet are administered by different agencies, at the federal and usually at the state level. Some programs have been designed primarily for the regular school population, but a portion of their funds is earmarked for the handicapped. Title III, the Vocational Education Act, and Headstart are three federal programs that have followed this pattern. A questionable accountability process has been built into each of these programs to “ensure” that the earmarked funds actually flow to the handicapped. Part of the problem of program coordination is overcome by assigning some of the programs to the Bureau of Education for the Handicapped, but BEH is responsible for managing only about half of the funds identified for special education of the handicapped.

The federal government’s role in the education of hearing and vision impaired children differs somewhat from its role in the overall education program for the handicapped. In the overall program, the largest percentage of federal funds is used

to *stimulate* state and local effort. In the education of hearing and vision impaired youth, the role appears to be more one of *direct service* or *basic service support*, in addition to stimulation. The federal schools for the deaf, and the Deaf-Blind Centers program, are examples of heavy federal involvement in the provision of service. The P.L. 89-313 program is an example of basic service support for state-operated or state-supported schools, a role that is relatively more expensive for the federal government. While the federal government provides only 12 percent of all funds specifically identified for special education, it provides some 27 percent of the identified special education funds for the hearing and vision impaired. (These percentages are for special education expenditures only. If the unknown amount of regular education expenditures going to the handicapped and the unknown amount of residential mental facility expenditures going for special education were included, the federal percentage would be lowered.)

There are several explanations for the differential federal role. First, the state-operated and supported schools receiving P.L. 89-313 funds place relatively heavy emphasis on the sensorially impaired. Second, vision and hearing impairments are the lowest-incidence handicaps, which implies that some programs must operate at the national level to achieve economies of scale. Higher education programs for the deaf, the Deaf-Blind Centers, and the educational media production programs are three examples in which federal or multistate involvement could be justified to achieve such economies. Third, the relative political strength of the various handicap groups historically has shaped the present federal program. The legally blind, for example, are generally regarded as being able to exert strong political influence through various lobby groups.

Among the problems in educating handicapped children, the most notable are inequitable distribution of service, insufficient resources, lack of information, and gaps in service. Three of the most significant gaps appear to be the lack of preschool education—especially for the hearing impaired, who need early assistance in developing language and communication skills—the deficient identification of these youth, and the inadequate provision of sensory aids.

The likelihood that a 5-to-17-year-old youth will receive any special educational assistance varies widely across the states. Two states appear to serve less than 10 percent of the visually handicapped, while five other states serve most of them. Similarly, five states appear to serve less than 10 percent of the hearing handicapped, while four other states serve most of them. Using BEH figures of the prevalence of youth aged 5 to 17 needing special educational assistance, we estimate that 21 percent of the hard of hearing, 72 percent of the deaf, and 55 percent of the visually impaired youth were served in the United States in 1972-73. In terms of the amount of assistance received per child in a special education program, as measured by average reported special education expenditures, variation across states is also extreme: from less than \$500 for each hearing or vision handicapped student served in several states, to more than \$3000 in several other states. Our analysis suggests that handicapped youth receive more assistance (as measured by expenditures per child served) in higher-income states.

Furthermore, a child's receipt of special educational assistance, and the amount he receives, are unmistakably and strongly dependent on where his parents live, which means that many handicapped children are denied special educational service because of where they live, or they are forced to move to districts where such services are available. Such a situation is undesirable from several standpoints. First, it creates disincentives for local districts to sponsor outstanding special education programs. If they do, they are likely to attract handicapped children from outside the district and necessarily raise the school budget or divert resources from

the regular education program. Secondly, it requires that families having handicapped children bear the burden of moving costs, possible loss of jobs, and the like, to obtain adequate public service. Third, it means that the children of parents who cannot or will not move will receive inadequate special education services.

Improvements are crucially needed in the delivery of special educational assistance to handicapped youth. Improvement is also needed in other services that are not strictly educational, but impinge on the successful implementation of special education programs; these include identification, sensory aids, and direction services, all discussed earlier.

The fraction of school-age handicapped youth receiving special educational assistance should be increased, with a concomitant increase in personnel and in the comprehensiveness of special educational assistance available in each geographic area.

Parents overwhelmingly point to special education as their handicapped children's most important need. These increases would reduce the inequity of present service delivery; the courts are moving in the direction of mandating such service as a "right"; such assistance appears to be cost-beneficial in an economic sense, as well as humanitarian, for the less severely handicapped (although economic data are not available to prove this conclusively); and such assistance appears to be justifiable on humanitarian grounds for the more severely handicapped.³

Cost, of course is the principal argument against this increase. Expanding service to all youth in need aged 5 to 17, at the same expenditure rate for special education (above the expenditure rate for regular education) prevailing for those currently served, would require an estimated total budget increase of approximately \$269 million a year (\$209 million for the aurally handicapped, \$60 million for the visually handicapped, using BEH prevalence rates.) Taken by themselves, these are not prohibitively high expenditures, but if a school district began serving all sensorially handicapped youth, it would probably come under extreme pressure to serve all other handicapped youth—and that would require adding about \$2.5 billion a year to special education budgets in the United States.

A start could be made by serving all of the functionally blind and the profoundly deaf, since their handicaps are two of the most severe and their numbers are small enough so that certain aspects of expanding service to the total population in need could be tested at relatively low cost. As the number of youth served grew, there would be an opportunity to expand programs in ways that would reduce the current inequity of geographic distribution of services. To permit the delivery of appropriate services, the comprehensiveness of types of special educational assistance available in each geographic region needs to be improved. At the state level, and in regions within the state if the prevalence of the handicap permits, assistance appropriate to each child's age, type of handicap, and degree of handicap should be available.

Of course, increasing the number of children served requires a concomitant increase in special education personnel and facilities. Using BEH estimates of the desirable ratio between students and special education teachers for the currently unserved population aged 5 to 17, we calculate that approximately 11,500 new specialists in education of the sensorially impaired are required: 9900 for the aurally handicapped and 1600 for the visually handicapped.

³ For example, assume a handicapped child receives 12 years of special educational services at an added cost of \$800 a year above the cost of regular education. The increase in monthly income over the working life of the child needed to offset the special education costs, discounted at 8 percent, is about \$108 per month. It is not difficult to conceive of 12 years of special education raising the earnings of the handicapped by this small amount—about 63 cents an hour. On the other hand, the increase in earnings necessary to offset a \$4000 per year added cost of special education is about \$540 per month.

Evaluation of the sufficiency of resources depends on the objectives one sets for special education. That is, unless one knows what has to be achieved, it is impossible to calculate the resources necessary to achieve it. Objectives can be framed by answering two questions: How many children should be served? What level and type of service should be offered? It is easy to say that every child should be served, and served so generously that he reaches his maximum potential. But with the limited amount of funds available both for current programs and for incremental changes, it is necessary to make hard choices between the number of children served and the quality of service. The current trend is to extend the program to more children rather than to increase the quality of existing programs. The implicit reasoning behind these priorities appears to be that existing programs are typically subject to minimum standards of quality (e.g., student-teacher ratios) to prevent their becoming ineffectual because of low budgets; and in many situations there are decreasing returns from additional investment per person served. That is, an additional dollar spent on a child already in a program will not buy as much in effectiveness as it would buy if spent on a child who has been receiving no service. The trend to expand services to more children is logical if one considers the parents' comments to us: they were generally satisfied with the quality of special education received, but reported difficulties in getting into the programs.

Potential federal activities to support expansion of special education services to handicapped youth include: direct provision of services; financial aid to state and local governments, with or without regulations; special educational vouchers; investment in service manpower and facilities; stimulation of service provision through research, demonstration, and information dissemination; and court rulings. Direct federal provision of services is probably not justified except for very-low-incidence handicapped population groups.

Several arguments can be marshalled to justify the federal government's assuming a larger share of the financial burden of special education. First, the poorer districts and states are at an economic disadvantage in serving their handicapped youth. Second, costs to the federal government of rehabilitation and welfare for the handicapped population can be reduced by investment in special education. Third, the state and local institutional framework for resource allocation decisions may embody incentives against providing services to minorities such as the handicapped, and federal financial intervention in this case may be justified in terms of protecting minority rights. And a fourth argument that might be advanced is that some level of government should fill the large unmet need; state and local governments are not doing the job; therefore, the federal government must provide categorical financial aid. Court rulings have the effect of forcing increases in the number of handicapped youth served by state and local agencies, and are becoming an important prod to equitable treatment. The lack of service to a large fraction of handicapped youth is partially caused, one might assume, by current program inertia and high start-up costs, in which case the federal government might adopt a major stimulative role including: special education teacher training, facilities construction, and identification on a large enough scale to fill the unmet need, plus federal categorical funding of costs of special education above the costs of regular education for all handicapped youth for a program expansion time period of perhaps five years (with a gradually decreasing federal contribution and a gradually increasing required state "match," thus allowing time for the increased state and local programs to "catch on"). Present levels of stimulative funding appear inadequate to meet the Office of Education's objective of special education for each handicapped child by 1980.

Preschool educational opportunities for hearing handicapped youth should be increased.

The principal argument in favor of this increase is the widely accepted belief among educators of the deaf that a deaf child's development will be seriously and perhaps permanently inhibited if he does not receive special assistance during the preschool language acquisition years. (Data are not available, however, to indicate how many youth would need less special education in later school years if they received that assistance.) For the profoundly deaf child, considerable attention is desirable; the hard of hearing child may need no more than a hearing aid so that he can develop language in the same manner as normally hearing children. Preschool instruction can be given directly to the child, as well as indirectly through parents, and programs to train parents to give instruction should be encouraged.

The principal arguments against this increase are cost and the lack of programs for identifying hearing-handicapped children. We have recommended that a preschool-age identification program be established. The cost of preschool-age education for the more severely hearing handicapped would not be prohibitive since we are speaking of a relatively small population. While such education might be desirable for all categories of handicapped youth, the argument for the deaf, based on the language development process as a function of age, is more compelling than any we have heard for other handicaps.

Several reasons explaining the present shortfall in the number of deaf youth receiving preschool education are evident. Many states do not permit state-supported preschool education and other states permit but do not mandate it. State regulation, then, offers little incentive for the local district to become involved with handicapped preschoolers. Nonexistent, untimely, or poor identification of these children of course prevents parents from seeking educational services. And even if identified, there are so few of these children that their parents would not constitute a very effective pressure group. Finally, no educational agency is presently responsible for serving this age group.

In reality, both hearing and vision handicapped youth could benefit from intervention in their training at an early age. The visually handicapped need training in using equipment, in mobility, and in other activities of daily living, and also in using their residual vision. Otherwise, they may become dependent on others rather than develop their own capabilities. Parents, especially if they do not know what the child is capable of doing by himself, may structure his environment in such a way as to limit development opportunities.

Federal initiative is perhaps more important for establishing preschool programs than for programs for older youth, since preschool age groups are generally not considered a responsibility of the state or local education agency.

Research and evaluation to obtain better planning information should be increased.

Research and evaluation can discover better ways of educating handicapped children, and document the results of existing practices. Both kinds of knowledge can be valuable to the planners of new and revised special education programs. At present, planners must proceed in the face of major information gaps. They especially need data on the size and characteristics of the served and unserved populations, and the costs, benefits, and effectiveness of various types of special educational assistance. Despite the lack of reliable information, annual special education expenditures exceed \$2.6 billion; reliable information should enable a more effective allocation of these funds.

We suggest, however, that research to create better educational methods should be of a lower-order priority than the evaluation of current methods and research on how demonstrably good practices can be disseminated to all youth in need. This call for improved research and evaluation is *not* meant to imply that current special

education programs are ineffective, or that the people who run them have major failings. On the contrary, these people are generally aware that information is limited about what appears to be an effective set of programs, and they are attempting to fill the gaps. We support those attempts and encourage an expanded effort, coupled with increased efforts to disseminate and put the results of research into use.

The rationales for federal activity in research and evaluation are clear. The benefits of research and evaluation accrue to all states; there are definite economies of scale in these activities; and considerable duplication of effort would occur if these activities were left solely to states.

Counseling

Professionals throughout the system undoubtedly do some counseling of the handicapped youth and his family, such as counseling on the nature, cause, and future course of the handicapping disorder by physicians; vocational counseling by school personnel and vocational rehabilitation counselors; and counseling of both parents and children by school and preschool personnel so that the handicap is understood and the child's total learning capacity is enhanced. We have already discussed direction, a special kind of counseling designed to provide guidance on what services the child needs and where to obtain them. Psychological counseling may sometimes be indicated to help youth cope with their hearing or vision handicaps, but the need is less than it would be for youth with pronounced emotional disturbances or youth who are both sensorially handicapped and emotionally disturbed. To assure that the service is provided, health care programs could include outpatient coverage of certain psychological counseling needs of handicapped youth.

While counseling is important, the parents we interviewed rated many other services more so; hence, we have chosen not to make any recommendations for federal action in the counseling area. However, we note that the Regional Direction Centers, if implemented, could help insure that a youth's total counseling needs are met.

Special Training

Availability of specialized training varies considerably according to the kind needed. If a handicapped youth needs speech therapy, he can often receive it from schools. Teaching of speechreading (lipreading) skills and other specialized training could be provided on an as-needed basis from local sources known to and contacted by a direction service. Other types of training needs, such as for mobility, use and routine maintenance of sensory aids, or for activities of daily living, are typically not the major responsibility of any single state agency and often are not widely available in public programs. Reliable expenditure data are not available, but we know most special training can be relatively inexpensive and can significantly improve the handicapped youth's life style. Again, if Regional Direction Centers were implemented, they could help ascertain the youth's need for these special types of training and match him with an appropriate server. We suggest, however, that the special education agency assume the primary responsibility for meeting special training needs because the skills imparted by special training bear directly on more traditional aspects of the education program and no other agency is likely to be as suitably equipped and in contact with school-age children.

While Vocational Rehabilitation programs provide special training along with vocational training, they do not reach young children.

Vocational Services

The Vocational Education program expends about \$6.1 million per year for hearing and vision handicapped youth, but data on the results are not available. Vocational or career education options available to sensorially handicapped youth through this program appear very limited. (See Chapter 8.)

Vocational Rehabilitation (VR) is the largest vocational service program. It provided a wide variety of services through state agencies to 6680 hearing and vision handicapped youth whose cases were closed in FY 1970. (A full description is contained in Chapter 9 and in R-1220-HEW, Chapter 5.) Each year about 33,000 hearing and vision handicapped youth enter the age range where they may need vocational services. Data on the number of case closures in FY 1970, taken as a percentage of the number of sensorially handicapped youth entering an age range where they may need VR services, are revealing: over 100 percent for deaf youth; about 10 percent for other hearing impaired youth; about 57 percent for totally blind youth; and about 21 percent for partially sighted youth. In addition, 4885 visually impaired youth, reportedly having either one good eye or some other visual impairment with acuity better than 20/70 (and who are therefore not visually handicapped according to the definition used in this report), had their cases closed in that year. The \$26.1 million expended per year for hearing and vision handicapped youth by VR results in an 84 percent success rate for the 52 percent of the young sensorially handicapped referrals accepted, with "success" defined basically as a favorable prognosis after 30 days of gainful employment. Visually impaired youth receive nearly twice the total expenditures received by the hearing impaired.

At the time of case closure, 86 percent were in the competitive labor market, 8 percent were homemakers, and 3 percent were employed in sheltered workshops. Average weekly earnings at closure were \$84, but about one-third earned *less* than \$64, the 1970 national "minimum wage" of \$1.60 per hour for a 40-hour work-week—despite being in the VR program for an average of 19 months from acceptance to closure and despite basic program expenditures of \$2103 per youth rehabilitated. Expenditures per youth rehabilitated varied extremely across the states for youth with the same type and degree of handicap; they averaged \$6167 for totally blind youth, \$2068 for deaf youth who are unable to talk, and \$1678 for youth with "other hearing impairment."

Our benefit-cost analysis of the VR program indicates that the program offers society a positive return of between \$1.10 and \$4.40 for each \$1.00 invested, depending on the type and degree of hearing or vision handicap. Even using more stringent assumptions than most previous evaluators have used, the program still appears to have economic benefits both to society *and* to taxpayers that exceed the costs for all eight categories of hearing and vision handicapped youth analyzed. In addition, positive quality-of-life benefits add much support to this program.

Although the federal government provides over 80 percent of the VR funds, along with program operating guidelines, the states play a major role. They operate the VR agencies, and state personnel directly provide some services, such as counseling and placement, and contract with vendors for other services, such as medical treatment and occupational training.

The federal government also supports state employment service agencies, which provided job information and/or placement services to about 11,000 hearing and vision handicapped youth in 1970, and expended about \$35 per client.

Other vocational programs are: the Presidential, Governors', and local Committees on Employment of the Handicapped, which primarily endeavor to educate potential employers and the public regarding the vocational abilities of the handicapped; Federal Employment of the Handicapped, a Civil Service Commission pro-

gram for applicants for federal jobs; and the Randolph-Sheppard Vending Stand program, which provides legally blind persons with employment in governmental buildings. Exclusive of vocational education, all other government expenditures on vocational services for hearing and vision handicapped youth totaled \$31.6 million in FY 1972.

While the vocational service programs we investigated are of clear positive value, several problems were still identified, including unemployment; little program effort to combat significant underemployment; insufficient funds to meet service needs; large inequities across states in the likelihood of being served and in expenditures per youth served; a questionable allocation of limited available VR funds favoring visually handicapped youth over hearing handicapped youth; a questionable allocation of limited available VR funds for service to relatively large numbers of mildly visually impaired youth; implicit program disincentives for desired behavior by service personnel; insufficient service personnel with special skills in helping hearing and vision handicapped persons; lack of effective coordination between various vocational service programs; inadequate outreach features in the programs; and reportedly low-quality State Employment Service assistance to handicapped persons.

Vocational services to hearing and vision handicapped youth can be improved.

The Vocational Rehabilitation program should be expanded to serve a larger fraction of the hearing and vision handicapped youth population.

This program not only improves the quality of life of youth served by increasing their ability to function more independently, to obtain employment, and to get higher-level jobs, but it also appears to yield economic benefits to society (reduced service cost later in life, reduced welfare, increased tax revenues, and increased earnings) that exceed the cost of the program. The need for additional facilities is also large. Under the present program structure, the expansion of service would come about primarily through federal funds.

Clear guidelines should be established on the categories of handicapped persons to be given priority in the receipt of Vocational Rehabilitation services, and existing incentives should be restructured so that those categories are given priority. The simplistic use and reporting of successful case closures should be replaced by a more sophisticated system.

One might assign highest value to serving those with severest handicaps (as the Rehabilitation Act of 1973 does) or to young persons, unemployed persons, persons who show promise of yielding high economic benefits in relation to cost, etc. Or one might take a more dynamic and flexible approach that depends mainly on the level of vocational impairment. For example, "normal" youth could receive no special vocational services unless they are unemployed after leaving school, in which case the state employment service would give them job information. All handicapped youth could be screened before leaving school, and mildly handicapped youth would automatically be offered both job information and placement assistance upon leaving school; then, if they are not vocationally successful, full Vocational Rehabilitation services would be given. Severely handicapped youth could be automatically offered Vocational Rehabilitation services beginning well before they leave school. Even before the Rehabilitation Act of 1973 was passed, we seriously doubt that legislators and VR program administrators really intended that VR counselors should draw a reported 69 percent of the young visually impaired clients to be assisted from the categories of "one good eye" and "other visual impairment," rather than from the more severely handicapped categories of "partially sighted" and "blind." Of course, it is possible that VR counselors are giving severely or multiply handicapped clients labels that incorrectly indicate a less severe impairment, so as

to lessen stigmatization. However, for visual impairments, the charge appears to be true that *some* VR counselors inflate success statistics by "creaming" —selecting easy-to-serve clients. To satisfy the intent of the Rehabilitation Act of 1973 to serve the most severely handicapped persons first, the Rehabilitation Service Administration needs to change the incentives affecting VR counselors, to formulate better definitions and to improve its reporting; among other things, reports should be disaggregated within each type of handicap by degree of severity.

Presently, the system regularly measures and reportedly rewards its personnel at least partially based on total successful closures and the percentage of successful closures made in relation to clients served. The use of gross numbers of successful closures provides disincentives for serving hard-to-rehabilitate clients, disincentives for an individual VR counselor to conserve on program costs, disincentives for offering a wide choice of occupations to clients, and disincentives for training clients for anything better than low-skilled, low-paid occupations. The much discussed, but as yet unimplemented, concept of disaggregating clients served according to the difficulty of their rehabilitation and to the type or quality of "gainful employment" obtained, is a good one. Using either a set of measures of individual counselor and agency "effectiveness," or a weighted measure giving higher value to higher-priority types of clients and results, would be a major improvement over the simplistic and partly counterproductive measure currently relied on.

Thorough evaluations should be conducted of state programs that yield significantly better than average gainful employment, range of occupations, and earnings results for handicapped youth, so as to determine desirable and replicable characteristics of those programs.

The different VR methods used throughout the 50 states present a wealth of relatively untapped data capable of shedding light on program effectiveness. The current system of reporting on individual clients is the most comprehensive of all those we observed in federally supported programs, but it still has some deficiencies; for example, the system does not offer very illuminating categories of reasons for rejection of clients or failure to rehabilitate clients.

The number of specialists in vocational services for the handicapped should be increased and their geographic distribution improved.

Special expertise is needed to serve handicapped persons; the need is especially critical for profoundly deaf clients with little or no oral communication skill. Most states have such specialists, but care should be taken that they are available at least in every major metropolitan region. This holds for both the Vocational Rehabilitation program and the State Employment Service program. Increased federal efforts in the area of professional service personnel training would help alleviate current deficiencies.

Coordination should be promoted between Vocational Education, Vocational Rehabilitation, and State Employment Service programs, and a mechanism established for outreach to all handicapped youth in their latter school years, with follow-up after the time of leaving school.

These three programs often operate fairly independently of one another at the client level, although they have very closely related purposes, and often have "coordinating committees" at the top management level. They also tend to serve clients that come to them, rather than setting out well-defined priority categories of youth that need service and then reaching out to find those youth. Regulations encouraging automatic referral to or outreach by VR for all handicapped youth, both those in school and those applying for State Employment Service assistance, would be inexpensive but would provide state VR agencies with fairly comprehensive rolls of potential clients from which they could select high-priority types of youth. One

possible follow-up mechanism not now used is to monitor former clients' earnings through Social Security records, although careful consideration must be given to privacy.

State Employment Service programs should be modified to provide more trained specialists in the placement of handicapped persons, and those specialists should be given caseloads well below those of current program personnel.

The current caseloads of State Employment Service personnel are so heavy that it is difficult for them to provide meaningful job information, let alone placement service, to handicapped persons. In addition, although the information systems used in the states are improving, they still leave much to be desired in matching handicapped clients with available jobs.

Transportation

Transportation to obtain services may sound like a minor problem, but it was cited many times in our survey of families with handicapped children because it is often costly and time-consuming. The handicapped population is widely dispersed, but service agencies are not. That is, transportation is not a problem primarily because the youth are handicapped, but because the service agencies are located as they are. Schools often provide bussing for handicapped youth, and should be permitted and encouraged to do so. Travel to specialized medical facilities located more than a set maximum distance from home could be paid for by health-care payment programs, so that vital medical treatment is not hampered by the small but important detail of the transportation cost of the youth and accompanying parent. And the Vocational Rehabilitation program can cover transportation costs to service facilities, if desired. If a handicapped child has to travel to receive a needed service, then those responsible for the service should be sure that transportation is not a problem. Because the matter is individually and locally determined, we do not recommend a federal role in transportation of sensorially handicapped youth.

Recreation and Social Activity

Opportunities for social activity and recreation are obviously vital components of the quality of life of handicapped youth, but are not now governmental responsibilities. We have no specific recommendations for government action in this area, beyond those presented for improving other service programs that may incidentally provide recreation and social activity or improve the youth's ability to participate in and benefit from those activities.

Personal Care

While almost all handicapped youth care for themselves or are cared for by their families, some small fraction are cared for in residential schools, in institutions for the mentally handicapped, in hospitals, and in foster homes. Some fraction of the families are financially needy and receive income maintenance that helps pay for personal care expenses for the handicapped child. We have no specific recommendations regarding personal care, beyond those presented for improving other service programs that may also directly or indirectly facilitate it.

Income Maintenance

Three basic kinds of direct and indirect income assistance exist: those providing

income to help meet the financial needs of handicapped youth through direct cash transfers; those contributing to economic security through human resources development, such as education and vocational rehabilitation; and those providing services other than cash transfers to the family. This section considers only direct cash transfers; the others have already been discussed. (See also Chapter 10 below, and R-1220-HEW, Chapter 7.)

In 1970, some \$635 million in income maintenance expenditures aided about one million physically and mentally handicapped youth; hence, the average annual per capita assistance expenditure was about \$635. Financial assistance to vision and hearing handicapped youth in 1970 was estimated to be \$18 million and \$25 million, respectively. The total federal, state, and local shares were 54.6, 34.6, and 10.8 percent, respectively. Four primary programs serve physically and mentally handicapped youth: Social Security Disability Insurance (SSDI); Supplemental Security Income (SSI) providing aid to the aged, blind, and disabled (formerly OAA, AB, and APTD); Aid to Families with Dependent Children (AFDC); and Income Tax Exemption for the Blind (ITEB). The estimated numbers of physically and mentally handicapped youth served by these programs in 1970 were: SSDI, 14,700; AB, 4000; APTD, 29,000; AFDC, 976,000; and ITEB, 9000.

Prior to the Social Security Amendments of 1972, most youth given aid were eligible not because of their handicaps, but because they were part of a family receiving Aid to Families with Dependent Children. However, the AFDC program does not allow for the added expense of the handicapped child. The 1972 amendments permit youth from needy families to draw significantly increased aid based upon the existence of a handicap under the new and much more equitable Supplemental Security Income program. SSI provides aid to the aged, blind, and disabled and does not have the age restrictions of the former AB and APTD programs, which not only excluded persons less than 16 or 18 years old in most states, but also fostered extreme interstate variation in assistance levels and eligibility standards.

The federal government uses two primary functional mechanisms to provide cash transfers: direct provision of assistance in the SSDI and SSI programs, and purchase of assistance through state and local agencies in the AFDC program. Federal involvement has grown to the point where the majority of the funds expended on needy handicapped youth are federal, and three of the five major programs are federally operated. Federal dominance has apparently evolved for two main reasons: state, local, and private sources have had insufficient financial resources to provide socially desirable minimum income levels to an acceptable fraction of the needy population; and under state and locally operated programs, a socially undesirable interstate inequity in the distribution of funds has prevailed.

There is a clear and present need to undertake research and evaluation to obtain much better planning information on the financial needs of handicapped persons.

Data on program accomplishment with respect to handicapped persons are woefully inadequate. Decisions on levels of financial assistance to the handicapped person and his family must be made based upon very little information, particularly in two essential areas: the extra financial needs of various groups of handicapped persons, and the adequacy of different levels of support to the handicapped person in terms of the total quantity and quality of goods and services that can be purchased with the assistance. The SSI program, with its new regulations, needs careful evaluation to see if it is functioning as intended and how well it is functioning. Since this evaluation information will be of national value and since the federal government supplies the majority of the income maintenance funds for handicapped youth, it seems logical for HEW, rather than individual states, to undertake the recommended research and evaluation.

Direct cash transfers to handicapped youth and their families, in lieu of other mechanisms of making service available, should be limited to coverage of normal daily living expenses and to relatively minor special service expenses.

The amounts needed to cover a handicapped youth's necessities of daily living, such as food, housing, and clothing, are relatively constant and predictable. With that major exception, expenditures for other important services either occur before the child is handicapped or known to be handicapped (and the family by definition cannot be given dollars in lieu of services) or are highly variable and often unpredictable expenses that are not uniform over time but depend on the child's specific needs of the moment. In the latter case, the financially needy family could be given an income supplement to cover the cost of the special services. We believe it is desirable, however, to avoid issuing such supplements routinely during time periods when the family does not need them. The family may not save the extra funds for the child's future needs, and even if it does, the savings may fall short of the amount needed when the time comes. If such funds are dispensed nonetheless, it is essential that their amount be based on the child's periodically assessed needs for major services. Further, since the child is the one who needs the special service but is not necessarily the one making expenditure decisions, we believe it highly desirable to protect both the child's rights and society's investment by requiring that major special income supplements above income maintenance levels for daily living be expendable only for meeting the specific needs of the handicapped child. Even if this requirement were faithfully observed, however, it still seems a needless complication. Funneling the money through the family rather than directly to the service providers adds one more link to the chain of moneyhandlers, while apparently offering no dominant advantages. In essence, we are recommending that the government maintain its current general operating policy of *not* giving dollars directly to the family in lieu of major services.

Either the income tax "extra personal exemption" program should be revised to include all severely handicapped persons with relatively low incomes, over and above legally blind persons who file a tax return, or the entire program concept should be restructured.

The present extra personal exemption program for legally blind persons who file a tax return is clearly discriminatory. If it is justified for the legally blind, then by the same rationale it is justified for the severely hearing handicapped. This program is questionable on the grounds that it provides "a little something extra" for one type of handicap but not for other types with apparently similar needs, for tax filers but not for children of tax filers, for persons with sufficient income to pay income taxes but not for others with lesser incomes, and provides the same exemption for high-income and needier lower-income persons. This program needs to be thoroughly studied and then revised.

One possible option would be to grant an extra one or two personal exemptions to each taxpayer and dependent who are severely handicapped. Another possible option would be to permit deduction of a portion of all necessary extra expenses incurred because of the handicap of the taxpayer and any of his dependents, with the portion dependent upon the taxpayer's income level and with a maximum ceiling on the amount of the deduction; this is implicitly a voluntary identification program with the incentive being reduced taxes. A third option would be a revised income tax program for handicapped persons that provides benefits ranging from nothing for relatively high-income taxpayers, to expense deductions for lower-income taxpayers, to an income "supplement" rather than an income "tax" for persons who are handicapped and in the lowest income range. Clearly, this income supplement for handicapped persons is one major and very flexible alternative to the

present Supplementary Security Income program of income maintenance for handicapped persons. Annual, voluntary qualification could be designed but could be conditioned upon a test for employability or for past participation in other programs, such as Vocational Rehabilitation. This recommendation applies to state and local, as well as federal, income-taxing authorities.

Government contact with youth in families receiving income maintenance represents an opportunity for identification of handicapping conditions, transfer of youth from AFDC to the higher-paying SSI program, diagnosis and treatment under Medicaid or some other health program, and direction to programs that can supply other needed services. This opportunity should be fully exploited.

Despite special provisions in the Medicaid program for identification and treatment of handicapped youth, and special provisions for referral of disabled financial assistance recipients to the Vocational Rehabilitation program, this opportunity is not being fully exploited. Under present programs, implementation of this recommendation would occur primarily through state agencies operating programs subject to federal regulations, which will need much more diligent enforcement than they presently receive.

Multiservice Recommendations

Our last two recommendations pertain to all services. One concerns special provisions for service delivery to the very-low-prevalence population of deaf-blind youth, and the other concerns the coordination and management of all federal service programs.

The federal government should continue its present role of directly funding comprehensive services to deaf-blind youth through a regional care network.

Youth whose hearing and vision are both severely impaired constitute such a small population (5300 children had been identified nationwide as of January 1973) that individual states generally have too few of them to mount an effective program providing the specialized intensive and comprehensive services they need. The Federal Government presently funds a nationwide network of ten interstate Regional Centers for Deaf-Blind Children through the Bureau of Education for the Handicapped. The Regional Centers are intended to identify deaf-blind children and offer comprehensive diagnostic and evaluative services, maintain a registry, develop consultative and training programs for both parents and service personnel, develop new programs and services where they are needed, and coordinate services offered by other existing agencies. The Federal Government also funds a National Center for Deaf-Blind Youths and Adults. The National Center is intended to provide comprehensive services through residential facilities, provide consultative aid to other organizations serving deaf-blind persons, demonstrate methods of service, train personnel, and conduct research on services to the deaf-blind.

We recommend that a strong, well-staffed, and well-funded Office for the Handicapped be created within the Office of the Secretary of HEW: to do effective short- and long-range planning for the many federal programs providing services to handicapped youth; to evaluate the costs and effects of all services, and existing and proposed federal programs, with respect to handicapped youth; to effectively coordinate those programs' efforts; to sense the needs for, provide guidance to, and enhance the dissemination of research and demonstrations; and to obtain and make use of information on all services to handicapped youth.

Given the present severely deficient quality of program information, planning, evaluation, and coordination, the creation of an office at a high level within HEW with responsibility for remedying this situation is clearly needed. But more than a

pro forma effort is required for the Office to be effective. The Office should have the staff and funding to do the abundant work needed, and to collect and analyze the information that is presently severely lacking. And the Office should have significant inputs to pending decisions on programs affecting the handicapped population so that informed decisions can be made.

SETTING INTERSERVICE PRIORITIES

The answers to questions of who gets what, when, and how, lie at the root of any government activity, form the basis for setting priorities among public service options, and determine the timing and means by which the various options are carried out.

To aid government officials in the formidable undertaking of answering these questions, several criteria have been developed that emphasize the salience of *resource consumption* at present and in the future, the *equity* of the distribution of present and recommended services, the *economic effects* of services to the handicapped, and the *quality of life* of the handicapped.

Priorities, Needs, and Objectives

To set priorities among services, one must consider how meeting the various types of needs of the handicapped population measures up against the criteria, and how well combinations of options further one's objectives. For instance, plausible types of objectives range all the way from developing the maximum potential of every handicapped individual, to helping handicapped persons be nondependent, to the control of long-run costs to the taxpayers incurred by serving the handicapped, and on to the control or minimization of short-run costs. (R-1220-HEW, Chapter 4, discusses each of these objectives in more detail.) Other types of objectives exist or could be developed, but these are at least representative of some distinct and potentially conflicting ones.

To determine whether and to what extent these objectives have been met or could be achieved at some future time, one needs measurement criteria such as those noted above. (R-1220-HEW, Chapter 11, contains a more complete discussion.)

To talk about the quality of life of the handicapped individual in terms of services and priorities among services, one could develop a hierarchy of services that begins with prevention and progresses as follows:

- Prevention
- Identification
- Direction
- Medical Treatment
- Sensory Aids
- Special Education
- Vocational Rehabilitation
- Income Maintenance

Prevention of the handicap not only obviates the need for any other services, but greatly enhances an individual's quality of life (with respect to a possible handicap). If prevention is unsuccessful, then the next most important services, from the individual's perspective, are early and correct identification and direction to prompt and proper medical treatment, since numerous potentially handicapping conditions can be cured or stabilized at a less debilitating level *if* they are detected early enough

and treated correctly. If a handicapping condition occurs or persists nonetheless, the next most essential service (for sensorially handicapped youth) is the provision of a sensory aid to minimize its effects. A significant number of impaired youth can *function* at reasonably high performance levels with an appropriate sensory aid, and consequently may need many other services less or not at all. But some fraction of the population will be functionally handicapped in spite of all efforts; achieving the best possible quality of life for these youth will hinge on the amount and quality of other supportive and remedial services available to them. Special education is clearly one of these, and logically precedes Vocational Rehabilitation—taken from the individual child's point of view as he matures—which in turn comes before the provision of income maintenance if vocational rehabilitation is not successful. Other services could be listed, but this represents a clear ordering of the minimum services intended to improve the quality of life led by a handicapped person. The ordering in terms of quality of life can be summed up in two phases: prevent the condition if at all possible; if it is not prevented, then do what is needed to compensate for the handicap.

If our society is interested, for example, in maximizing the future economic benefits accruing to it, the list of priority services will be identical to that which we discussed for improving the individual's quality of life, with the sole exception of income maintenance, which would not be a high-priority service.

If society wishes to limit short-term costs but still achieve many long-term economic benefits, the basic list of services to be stressed is truncated even more:

- Prevention
- Identification
- Direction
- Medical Treatment
- Sensory Aids
- Special Education (relatively low-cost-high-benefit forms)
- Vocational Rehabilitation

In addition to income maintenance, expensive forms of special education are not stressed in this hypothetical case since the service in general is often very costly and the economic benefits in relation to costs appear low compared with those of the other six services listed. For example, we have been able to demonstrate that Vocational Rehabilitation, even under the most stringent assumptions, is highly cost-beneficial (see Chapter 9).

When equity is stressed over other criteria, a clear case can be made for maximizing effort in the identification and direction services. Fair and equitable treatment implies that persons in similar circumstances with similar types or degrees of handicap will be found and directed to appropriate and similar care. That is, an equity bias in objectives can focus mainly on maximizing chances of finding and guiding the handicapped to other services. Whether and how fully those services are provided is related to other criteria and objectives, such as cost, quality of life, and economic benefits.

Priorities on Recommendations

We have developed several recommendations for improving services to handicapped youth in this report, with emphasis on hearing and vision impairment. The choice by government officials on which, if any, to implement depends on the objectives chosen and on the level of effort the government is willing to make in improving services to handicapped youth.

To summarize our recommendations and to direct attention to some of the more general strategic possibilities, we consider four scenarios of what government might do to improve services, illustrated in Table 2.1, as a function of government officials' decision on the desired level of effort and objectives. Many such scenarios could be generated with the information presented in the table, but these stress four major possibilities: limited or no change in the level of effort, but significant management improvement; minimal change; modest change in the current effort, tied to major long-term benefits; and substantial change in desired level of effort to meet the full needs of handicapped children. We caution that each column heading, such as "Modest Level of Effort," applies to the aggregate of all recommendations in the column. Any single recommendation may require less than a modest effort. It may also be very inexpensive and yet of highest priority in an alternative strategy to the ones listed in the table.

Status Quo Level of Effort. The status quo level of effort appeals especially to those interested in holding the line on, or even reducing, short-term expenditures. The wisdom of short-term economizing on services to impaired children can be challenged on more than one ground, including that of long-term economic considerations. For example, many disabling conditions are preventable, need not be handicapping if adequate and timely services are provided, and are, in terms of an individual's lifespan, considerably more expensive than short-term, often one-time, prevention service costs.

This is not to say that maintaining the status quo in terms of the level of fiscal effort also means maintaining the status quo in terms of management practices and institutional structures and functions. On the contrary, if one prefers to hold the line on costs, there are still many recommended changes that can be carried out to enhance control over the system's operation and to improve the quality and equity of services already provided. Even the quantity of services can be increased by improving efficiency and focusing on services that are cost-beneficial in the short run as well as the long run. In fact, adopting all recommendations listed in the column labeled "Slight or No Change" in desired level of effort should have these general effects. Included in this list are many information, management, and institutional improvements as well as a recommendation that could lead to trimming back one large program (MCHS). Slight or no-cost recommendations are made for each of the eight major service need areas.

Beginning to Face the Facts. In this scenario, outlined in the "Minimal Increase" column in Table 2.1, it is assumed that a minimal increase in the level of effort is desired, in recognition of the facts of the large unmet needs of the sensorially handicapped, inequities in service delivery, gaps in services, and lack of control of the service system.

Identification and direction are vitally important, but underdeveloped, services that help resolve each of these problems. If one wanted to move slightly beyond the status quo level of effort, improving and creating identification and direction services according to the specific recommendations made for each would be a relatively inexpensive and, in our view, beneficial and efficient way to do it. All status quo "Slight or No Cost" recommendations would also be implemented in this case.

"Facing the facts" implies that those responsible for the handicapped service system will make concerted efforts to find and then direct a maximum number of the handicapped to the services they require. The present level of government effort for other services could be maintained by setting priorities on who gets those services, and giving the others needed information so they can seek services privately. For those concerned with short-term economizing, this scenario should not be too hard to accept; identification and direction are both relatively low-cost services

Table 2.1
SUMMARY OF RECOMMENDATIONS BY DESIRED CHANGE IN LEVEL OF EFFORT

Service Need	Recommendations by Desired Change in Level of Effort			
	Slight or No Change	Minimal Increase	Modest Increase	Substantial Increase
Direction	Evaluate and pilot test Regional Direction Centers for Hearing and Vision Handicapped Youth	Create a national network of Regional Direction Centers		
Identification	Increase program evaluation and applications research to discover suitability for widespread implementation Require various types of service personnel to report handicaps	Improve and expand preschool identification programs Implement screening programs to reach every young school age child		
Prevention	Coordinate preventive research and operational programs		Vigorously pursue modified rubella immunization program Cover prevention services (without deductible) under Medicaid and proposed National Health Insurance	
Medical treatment	Evaluate Maternal and Child Health Service programs; consolidate resources on a few programs, and terminate others Consider consolidation of Medicaid and Crippled Children's Service programs Improve Medicaid program operations Improve medical treatment data collection and usage Narrow the gap between research and medical applications		Increase resources available to Crippled Children's Service program in the short term Develop and implement a National Health Insurance program covering all handicapped youth, with special provisions for their needs	
Sensory aids	Require medical exam prior to receipt of certain sensory aids Narrow the gap between research and application of sensory aids		Assure that all sensorially handicapped youth receive needed sensory aids	
Special education	Improve evaluation and planning information		Implement preschool special education for all youth who are severely hearing handicapped	Increase the percentage of handicapped youth served; increase the number of special education teachers; increase the comprehensiveness of types of special education available in each geographic area
Vocational services	Establish Vocational Rehabilitation service priorities; adjust incentives and reporting Increase program evaluation to discover suitability for widespread implementation Coordinate VR, Voc. Educ., Spec. Ed., and State Employment Service Activities		Expand the Vocation Rehabilitation program Modify the State Employment Service Program to provide more trained specialists and lower caseloads	
Income maintenance	Conduct research and evaluation; improve information Provide direct cash transfers to needy families for coverage of normal daily living expenses; use other mechanisms to provide other services		Insure that all Aid to Families with Dependent Children (AFDC) child-recipients receive screening and treatment under Medicaid, and direction to other services	Either revise the extra personal income tax exemption program for the legally blind to include all severely handicapped persons, or restructure the entire program concept Transfer handicapped AFDC child-recipients to the Supplementary Security Income program
Multiservice	Maintain the current federal role in serving deaf-blind youth Create a strong and vital federal Office for the Handicapped to obtain information and plan, evaluate, and coordinate services	Adopt all "Slight or No Change" in desired level of effort recommendations in each service need area	Adopt all "Slight or No Change" and "Minimal Increase" in desired level of effort recommendations in each service need area	Adopt all "Slight or No Change," "Minimal Increase," and "Modest Increase" in desired level of effort recommendations in each service need area

producing many positive individual and system benefits. Earlier we presented arguments why more identification is preferable to the status quo, even if the level of other services is not increased.

The notion of "beginning" contained in this scenario's label refers to the fact that at some future time a fraction of the presently unidentified and unserved handicapped will need other services (Chapter 4). The exact fraction is not known, but it is clear that it will be far less than the fraction who are unidentified now, since improved early identification, direction, prevention, and medical treatment will have eliminated or alleviated many handicapping conditions. Furthermore, the provision of adequate identification and direction will not happen overnight, nor will the increased demand for services materialize instantly or uniformly for all kinds and degrees of handicaps throughout the country. There will be time to move beyond simple fact-finding, and there will be visible clues as to which way the public and private service programs can head to begin filling the gaps in available services.

A Modest Proposal with Long-Term Benefits. A next, "Modest Increase" in level of effort as shown in the corresponding column of Table 2.1, could logically begin with a full-scale attempt to prevent as many handicaps as possible; would include good-quality medical treatment for those not prevented, to cure or stabilize the threatening condition and thus reduce the total amount and degree of handicapping in the population; would include the provision of sensory aids to those needing and able to benefit from them; and would include the administration of Vocational Rehabilitation to minimize the economic disadvantage of the handicapped individual.

For a long time and in various ways, responsible officials have promised much in the way of serving handicapped citizens and in reducing the extent of their dependence on public support. Delivering on those promises certainly costs something in the short run, but the long-term payoffs in human, societal, *and* economic terms for implementing the recommendations associated with prevention, medical treatment, sensory aids, and vocational training have all been shown to be positive—and distinctly so in most cases. The "Little or No Cost" level of effort, and the "Minimal Increase" level of effort recommendations would also be adopted in this scenario.

One might argue that "income maintenance" is important and should not be overlooked since it is necessary for some persons. We agree, but stress the development of all other, logically prior, services capable of reducing the future need for welfare payments. A special educator might find fault with this scenario. "After all," so a hypothetical criticism might proceed, "special education is a vital element needed to prepare these children for life, the child has a right to special education, and you have already told us that a large fraction of those needing special education are not getting it." We strongly agree, and we recommend substantial increases in special education expenditures, but point out that in this scenario it is assumed that *government officials do not want to substantially increase the level of effort*; our primary special education recommendation requires a substantial increase in level of effort and hence could not be implemented in this hypothetical case of a modest increase in level of effort. However, without substantial increase in cost, one could focus upon the education of preschool hearing impaired children and provide adequate sensory aids, at as early an age as possible, to reduce the extent of handicapping and hence the total need for special education in the population later. The points in this modest level of effort scenario are not to ignore special education and not to cut present levels of special education programs, but to concentrate *expansion* of efforts on preschool special education and on other services that do not require a substantial increase in level of government effort. Again, we are describing only

one strategy that might be adopted in setting priorities among our recommendations; we could also develop others that more heavily stress special education.

Meeting All the Needs. To meet criticisms such as those just outlined, and to implement all of our recommended changes, one might add to the three previous scenarios the substantial resources required to furnish good-quality special education to all handicapped children, and to guarantee income levels at or above subsistence, as outlined in the last column of Table 2.1. We assign high value to these recommendations, and have deferred them to this scenario only because of their high cost.

Still, the fact remains that the unmet and inadequately met service needs of handicapped children are great.

PART II

NEEDS OF HANDICAPPED YOUTH

Part II details our findings and recommendations for improving services to handicapped youth, with a chapter devoted to each of eight major service needs: prevention, identification, direction, medical treatment, sensory aids, special education, vocational services, and income maintenance.

Chapter 3

DIRECTION

INTRODUCTION

In view of the considerable sums of money expended by government and the private sector, why are the care and services provided to handicapped youth so deficient in many important ways, and why do many children still receive no services, the wrong services, or inadequate services?

Certainly, it is not because the country lacks programs for handicapped youth—we have discussed over fifty major programs in our survey of the current federal effort, and there are hundreds of state, local, and private initiatives. Certainly, it is not because parents of the handicapped are resigned or lethargic—many of them make heroic efforts to secure services for their children. And certainly, it is not because of significant deficiencies in the quality of care available—in 1973, the United States boasts some of the most advanced methods and technology ever devised.

Perhaps the easiest explanation would be to blame inadequacy of funds, and it is true that more money would certainly help. But resource insufficiency alone is not the answer to a basic problem that we find pervades nearly all aspects of the system: as it stands, the system currently delivering services to this nation's handicapped is so complex and disorganized as to defy efficient and effective operations.¹ Not all problems would be solved by pouring more money into the system without doing something about its disorganization and complexity. The \$4.7 billion already spent annually could be used more effectively.

Specialization, fragmentation, and bureaucratization without coordination and direction underlie poor system performance. The tangled array of service programs severely taxes parents' ingenuity, perseverance, and courage as they thread their way through the official labyrinth seeking services for their children. Fully two-thirds of the parents we interviewed said they had difficulty in obtaining appropriate services.² Their own words express their frustration and despair far more poignantly than could the pedestrian language of a research report:

The parents are over a barrel . . . whenever the mother of a "problem child" questions practices or "makes waves," the administrators threaten to exclude the child, and there is nothing that can be done about it.

There is no parental counseling, no referral; we were willing to try just about anything . . .

The woman offered help, and I almost cried because I was so grateful . . .

. . . a chain of talking and talking and talking . . . [and] stumbling around from place to place . . .

¹ Todd R. LaPorte (ed.), *Organized Social Complexity: Challenge to Politics and Policy*, Princeton University Press, Princeton, New Jersey, to be published in 1974. LaPorte deals extensively with the issues particularized in the instance of the handicapped service system.

² See Chapter 11 for a summary of these interviews.

There are so many government agencies, the people don't know *where* to go.

I don't even know what questions to ask.

Each major service program is designed to meet rather specialized needs; each has generated special constituencies and nurtured special interests; and each has its own separate budget, often not formulated according to any reasonable assessment of children's actual needs. Pity the unfortunate child who does not meet the letter or spirit of the law as "interpreted" in a federal or state bureau.

Some services are not a major responsibility of any program (see Table 3.1). We spend billions of dollars caring for handicapped children but, as following chapters demonstrate, we have traditionally spent very little on prevention or identification activities. This lack of responsibility for certain services is especially telling with respect to direction.

Direction is the periodic and systematic matching of a child's needs with the proper mix of services to satisfy those needs. Individual needs change, for instance, as the child ages or improves in response to services; a system's capacity to serve is dynamic, too. To put it somewhat differently, then, direction is an information-based service designed to match individual needs and local service system capabilities as both change.

Our society's service system is faced with an urgent need to become child-centered, not specialty-centered. Currently, agencies and professionals are responsible for providing only one or a select few specialized services. Even assuming that each agency and professional performs well, the fact still remains that each single service meets only part of the child's overall needs. We must begin to regard our handicapped children less as a faceless statistical group, and more as individual

Table 3.1

SERVICE COMPONENTS OF FEDERAL AND STATE AGENCY PROGRAMS FOR HANDICAPPED YOUTH

Type of Service	Type of Federal and State Agency				
	Health	Welfare	Special Education	Vocational Services	Mental Health and Retardation
Direction	--	m	--	--	--
Identification	m	--	m	--	--
Prevention	m	--	m	--	--
Counseling/psychiatric care	m	m	m	M	M
Medical/surgical treatment	M	m	--	m	m
Education	--	--	M	--	--
Special training	--	--	m	m	--
Vocational training	--	--	m	M	--
Job placement	--	--	--	M	--
Sensory aids/other equipment	m	m	m	m	--
Recreational/social activity	--	--	m	--	--
Personal care	m	--	m	--	M
Income maintenance	--	M	--	--	--
Personal training	m	m	m	m	m
Construction of facilities	m	--	m	m	m
Research	m	--	m	m	m

SOURCE: Rand report, R-1220-HEW, p. 15.

NOTE: M equals major component; m equals minor component; a dash (--) indicates little involvement.

fellow beings worthy of the utmost in respect and dignity—and attention. What is needed is an institution specialized to the job of looking at the child as a total human being.

The handicapped service system is not alone in suffering a lack of direction. We find it encouraging that a group of urban researchers, operating on a matter substantively separate from ours but conceptually similar to it, arrived at the same conclusion we did:

New institutional arrangements should be designed to use federal aids or grant conditions to help families learn about services that are available to them, to sort out what is available, to combine or help combine appropriately the many services (and their facility supports).³

This captures the essential spirit of what we mean by direction, but we develop and flesh out the concept considerably.

The remainder of this chapter discusses current service programs and their problems, desirable characteristics of a well-run direction service, some existing direction centers that are promising partial models, and some foreign models. The chapter concludes with a detailed discussion of the following recommendations for Regional Direction Centers for Hearing and Vision Handicapped Youth. When fully tested and developed for this population, the concept might be extended to include all handicapped youth and adults.

SUMMARY RECOMMENDATIONS FOR IMPROVEMENT

- Undertake full-scale evaluations of existing centers that are the most promising partial models for Regional Direction Centers, so as to learn their strengths and weaknesses and identify features worth incorporating in a nationwide network.
- Following those evaluations, conduct a detailed implementation analysis and then create five to ten pilot Regional Direction Centers for Hearing and Vision Handicapped Youth around the country. Such pilot operations should themselves be carefully evaluated.
- Incorporate, in the Regional Direction Center design, needed improvements revealed by the pilot projects, and expand the concept as rapidly as possible into a complete nationwide network of Regional Direction Centers.

CURRENT PROGRAMS

As indicated in Table 3.1, the direction service is not a main order of business for any of the various types of federal or state agencies serving the handicapped. In one type of agency where such activities are carried out, public welfare, direction is not a central concern but occurs only tangentially as a social caseworker might be required or inclined to assess a client's needs, search out the appropriate services, and then monitor the results.⁴ However, this program is restricted to the poor, social workers generally have heavy caseloads and are not rewarded for "direction," and they do not have the information needed to direct the youth we are concerned with here. The Maternal and Child Health Service also sponsors programs that do limited

³ Selma J. Mushkin et al., *Services to People: State and National Urban Strategies*, Public Services Laboratory, Georgetown University, Washington, D.C., 1973, pp. 16-18.

⁴ See Rand Report R-1220-HEW, Chapter 7.

noncomprehensive referral.⁵ Vocational Rehabilitation programs can provide a comprehensive range of services, but these do not reach young children, and services must be aimed at achievement of a vocational objective.⁶ Schoolteachers and nurses sometimes help parents find other needed services. Pediatricians sometimes help direct the family. In some states, the "Commission for the Blind" agency provides limited direction service to a segment of the handicapped population.

In general, however, direction is a distinctly underdeveloped and undersupplied service that is no one's prime responsibility. Follow-up and redirection, implicit in the notions of "periodic and systematic," are particularly underdeveloped. No one really provides this service except for isolated and dedicated professionals providing other services, who must make extraordinary and usually costly efforts to understand the overall system well enough to advise in areas outside of their particular service competence. Comprehensive information about the system is not generally available, and until it is, direction will remain stunted and erratic.⁷

The upshot is that parents are confronted with an intricate maze for which there is no map, and are left almost entirely to their own devices to thread their way through it. Few of them know much if anything about the various programs when they start out, and there are too few guides that give the facts in plain unvarnished English on what is locally available and what to do to get it. But even the simple facts are not enough; parents need to be fairly sophisticated, and must set to work mastering the ins and outs of a complex, interlocking, and sometimes competing set of bureaucracies and professions. Even after they have succeeded in obtaining services for their children, the possibility remains that alternative services they are unaware of might do the job better. Although ignorance may be bliss, and a parent may report that he is "happy" with the services his child is currently receiving, it is regrettable that, without the aid of a quality direction service, he cannot tell if some other service might not be better for the child, short of experiencing it.

PROBLEMS WITH DIRECTION SERVICES

Matching the Child with Appropriate Programs

The symptoms of the system's direction deficiencies are everywhere evident. As with medicine, this disorder requires a thorough description of its signs and symptoms before any diagnosis can be advanced.

Parents are not made aware of what services are available and what their child is entitled to receive. There are no reliable sources of local information that routinely assist the parents of handicapped children. This lack of information and a systematic way of matching the child with the appropriate set of needed services is the major problem.

Records are generated by many different agencies as the child moves, characteristically in chain-like fashion, from one service provider to another. There is no comprehensive compilation of all information generated by the individual child, with the immediate result that rediagnosis and recertification are commonplace.

Data that are collected reflect specialized institutional biases. Measures tend

⁵ Ibid., pp. 215-220.

⁶ Ibid., Chapter 5.

⁷ See *ibid.*, pp. 82, 93, 127, 136, 169-170, 199, 201, 207-208, 210-214, 221, 232-233, 263-265 for a detailed recitation of direction deficiencies.

therefore to be unidimensional and programmatic, and to miss much of what is happening to the individual.

Without the records a direction center could keep, problems arise in interpreting data. For instance, does an increase in the reported incidence of a disorder reflect an actual trend, or is the disorder merely being identified more vigorously? If such an increase is noted, is the information "translated" into messages to separate parts of the service delivery system so that adjustments should be anticipated at some future date to reflect the shift? Direction Centers could do this. The tragedy of rubella-caused handicaps in children is an obvious case in point. Since at least 1964-1965, the rubella-caused bulge in the incidence rates of aural and visual handicaps has been known, but there is little evidence that separate parts of the service system were forewarned, or that the system prepared for and responded adequately to these changes.

Data are usually outdated by the time they are finally reported, and once reported, they characteristically are cross-sectional not longitudinal. Planners have to resort to educated guesses to make marginal, time-dependent adjustments in service supply in the absence of time-series data on service demand.

Data often exist, but not in the public domain. Health information is particularly susceptible to this limitation, as in the case of the severely handicapped children of those wealthy enough to afford private services, or in those cases where a social stigma is associated with the disorder. No one has reliable information on how much aid is provided to the aurally and visually handicapped by churches, voluntary agencies, and specialized private agencies devoted to narrow classes of handicap.

The dissatisfied parent is often at a loss to know where to take his grievances, real or imagined, for settlement, or whether grievances are handled at all. Unfortunately, very few agencies are specialized to the redress of administrative or legislative oversight, and redress mechanisms within service agencies are generally very cumbersome, with the result that a parent has little or no effective recourse.

Families typically proceed serially from agency to agency. In the process they are liable to be "captured" by one agency whose services may appear to the parent to be adequate, or at least better than no service at all. The degree of misdirection owing to "capture" is simply unknowable, given the present state of information in the system. That it exists, however, is unquestionable; likewise indisputable is the knowledge that it results in a less than optimal or comprehensive delivery of required services.

Different Perspectives

One way of better understanding direction problems is to examine the process responsible for it from the perspectives of several of the main participants: parents, professionals, and decisionmakers.

Parents. After all is said and done, the parent bears ultimate responsibility for the handicapped child. Our society has consistently and clearly operated to give a parent the widest possible latitude and license for child rearing.⁸ However, a parent does not *have* to secure fully adequate health services, feed his child properly, provide a solid home environment, care about the emotional development of the

⁸ This is a main issue underlying weak and hard-to-enforce child abuse statutes. Mentally ill parents also present extraordinary problems that are frequently "insoluble," due in large part to this durable societal norm. See E. Pavenstein and V. W. Bernard (eds.), *Crises of Family Disorganization*, Behavioral Publications, New York, 1971, especially, V. W. Bernard, "Young Children of Mentally Ill Parents." See also Vincent Fontana's recent popularized account, *Somewhere a Child is Crying*, Macmillan, New York, 1973.

child, or even feel and convey those basic instincts commonly labeled "love."⁹ About the only area where society demands adequate minimum service is education, but as recent class-action law suits brought on behalf of the mentally retarded in several states show, even this minimal societal demand has not necessarily held for *handicapped* children.

Over-protective parents create problems of a quite different sort. Parents of handicapped children may internalize the guilt they associate with having a defective child; their resulting over-protection works to perpetuate the handicapped person in the role of the dependent child.¹⁰ There are varying degrees and manifestations of the problem, but it is understandably common and ordinarily works to limit a child's participation in the decisionmaking and mistake-making process of growing up.¹¹

Our society operates on the pervasive but erroneous assumption that the parents of handicapped children, like any other consumers, have unrestricted choices about the services they obtain for their children. In fact, most parents have neither the resources, nor the information on which to base choices.¹² Furthermore, existing institutions sometimes exacerbate the problem with unwitting incentives to use one service mechanism rather than another, e.g., insurance plans generally contain incentives that encourage differential use of facilities and services and discourage active exploration of creative and less costly alternatives.¹³

The reality of the situation is that the parent generally is an ignorant consumer.¹⁴ He does not have all the information needed to assess the services received and to choose among alternative service providers. Both of these essential truths have consequences for the overall system.

Because the parent does not have all the information needed to assess service well,¹⁵ he may receive either too much or too little of that service. With medical services, for example, a person may be "overdoctored," receiving more services than he actually needs or would buy if he were fully aware of their effectiveness; or he may be "underdoctored," receiving fewer services than he needs or would buy if he were less ignorant and could afford them. The latter case is an error more likely to afflict the poor;¹⁶ the former is a rich man's error. Traditional market signals are

⁹ This is not a frivolous point. It formed the basis for an interesting presentation by Mr. Fred Krause, Executive Director of the President's Committee for Mental Retardation, to the 24th Annual Convention, National Association for Retarded Children, Anaheim, California, November 1973.

¹⁰ Olga Lurie, "The Emotional Health of Children in the Family Setting," *Community Mental Health Journal*, Vol. 6, No. 3, 1970, pp. 229-235.

¹¹ S. Chess, A. Thomas, and H. G. Birch, *Your Child is a Person*, Simon and Schuster, New York, 1965.

¹² William J. Horvath, "Organizational and Management Problems in the Delivery of Medical Care," *Management Science*, Vol. 14, 1968, pp. B275-B279. Horvath is one of the few investigators who have attempted a comprehensive view of the medical system. Such a perspective can be almost as revealing as it is distressing. See *idem*, "The Systems Approach to the National Health Problem," *Management Science*, Vol. 12, 1966, pp. B391-B395.

¹³ One of the main objectives of an ongoing National Health Insurance social experiment is to examine the effects of such embedded assumptions and incentives in as controlled an environment as is practicable. See Joseph P. Newhouse, *A Design for a Health Insurance Experiment*, The Rand Corporation, R-965-OEO, November 1972.

¹⁴ Richard Zeckhauser clarified several of the key points in this portion of the discussion. Private conversation, February 1973.

¹⁵ Arnold I. Kisch and Leo G. Reeder, "Client Evaluation of Physician Performance," *Journal of Health and Social Behavior*, Vol. 10, No. 1, 1969, pp. 51-58, is an eye-opening, empirical investigation of the main points.

¹⁶ Frank Reisman et al. (eds.), *Mental Health of the Poor*, The Free Press, New York, 1968, esp. pp. 88-109.

not much help in resolving the matter.¹⁷ There is no clear-cut relationship between the price of a service and its general quality or specific appropriateness for a given child. For example, a relatively inexpensive, but appropriate, correctly fitted, and well-maintained hearing aid certainly is better than a costly one that lacks these properties; but the ignorant consumer who does not know the difference, may well put his trust in the costlier one because "they couldn't charge that much if it weren't really better."

When a parent is unable to choose effectively among providers of a common service or to determine the appropriate mix of required services for his child, what does he do? Traditionally, he asks a physician. But the physician, except for the unusual "resource man," does not have the amount and kind of information needed, either; it is understandable that he has few incentives to learn details about the whole service system in his locale, or to take time away from his specialty to give advice about such diverse matters as special education, rehabilitation, or financial assistance—nor should he. Social workers often fill the information breach, but with a large and diversified clientele and with little or no specific preparation, this alternative is a far from optimal solution to the problem.

The problem has been discussed by economists from time to time.¹⁸ One finding is that lack of information is a basic cause of the large and inequitable differentials in the amount and quality of services delivered by the private and public sectors and in different regions of the country¹⁹—differentials repeatedly pointed out in our companion report R-1220-HEW.

Professionals. Professionals are commonly captives of their professions—their imperatives, perspectives, and tools. Psychiatrists, mostly liberal in their general views about humanity and human behavior, sometimes become very conservative when it comes to specific details about service delivery.²⁰ They wear psychiatrists' glasses. Ophthalmologists wear glasses of a different refraction and tint, teachers wear yet another, and so forth.

To be a specialist means that one has concentrated on a limited field of knowledge; however, there is a mismatch of impedances, to borrow a communication term and concept, between this specialized information and the general, comprehensive information required by the family of a handicapped child. The family needs a great deal of information, at not too detailed a level, compiled in an easy-to-understand format or package, and touching on all matters affecting the particular child and his changes in the future.

The artificial boundaries created by fractionalized professional groups have led to compartmentalization, not integration, of services available to handicapped children. Specialized services are required, but those providing them do not have the time to appreciate the client as a *whole* person. And a limited perspective, trained into the specialized professional and reinforced in daily practice, intensifies his

¹⁷ Tibor Scitovsky, "Some Consequences of the Habit of Judging Quality by Price," *Review of Economic Studies*, Vol. 12, 1944-45, p. 101; and Andre Gabor and C.W.J. Granger, "Price as an Indicator of Quality: Report on an Enquiry," *Economica*, Vol. 33, February 1967, pp. 43-70.

¹⁸ George Stigler, "The Economics of Information," *Journal of Political Economy*, Vol. 69, 1961, pp. 213-225.

¹⁹ S. A. Ozaga, "Imperfect Markets through Lack of Knowledge," *Quarterly Journal of Economics*, Vol. 74, 1960, pp. 29-52.

²⁰ The issue has been treated clearly and compassionately in John E. Kysar, "Reactions of Professionals to Disturbed Children and Their Parents," *Archives of General Psychology*, Vol. 19, November 1968, pp. 562-570.

isolation from specialists in other fields.²¹ In the words of another of our survey mothers,

No one ever put all the pieces together. We only got the service that we asked for. No one ever tried to put all the clues together to move beyond the immediate problem. Doctors were not concerned. They kept coming up with the same diagnosis and did not listen to me or look through the histories.²²

"Putting the pieces together" is what direction is all about.

Little wonder that we find so many parents are distraught and bitter over the specialist's "lack of concern" and mystifying lack of information about other types of services the child needs. We demand entirely too much of the specialist when we expect him to be a generalist in providing complete information about the whole child—that is not his job, although people often imagine it to be, particularly the parents of a handicapped child.²³

Decisionmakers. Specialization has its administrative and political features, and its implications are none too good for the handicapped child and his family. The number and diversity of the individual agencies have created a domestic situation of curious proportions, characterized by a strange construction put upon "responsibility." One is responsible only for actual events; if little or nothing happens, then it is hard to be "irresponsible," in the bureaucratic sense. Consequently, except in a crisis, the safest bureaucratic course is to change nothing. This is a possible rationalization, for example, of the observed noncommunication of research results to the more operational segments of the overall service system. Not only are the links among those specialized in research and those concerned with service delivery tenuous or nonexistent, but there are disincentives that reinforce customary behavior.²⁴ An informational service should take this into account.

Bureaucratic pathologies, many of which are firmly rooted in the size and diversity of administrative systems, are well known and have been discussed in many standard works.²⁵ Disorderly symptoms are indicated in many aspects of the system serving handicapped children and youth; they include a penchant for treating administrative systems in isolation, a failure to deal effectively with clients as total human beings, and restrictions that inhibit the client from having direct access to the administrative apparatus, a pathology thought to be especially severe for the poor.²⁶ Because of bureaucratic complexity, in short, there is less than comprehensive interest demonstrated for the client, and the system assigns no specific responsibility for the client's overall welfare and treatment. The responsibility is diffused throughout the system, and the more complex the system, the more the responsibility is diluted.

The informational implications of these pathologies are several. Specialized agencies at best collect data for their own narrow operational purposes, not for sharing with other agencies. As a result, there is no general source of factual information and material about the handicapped.²⁷ Besides not transmitting even

²¹ This point is made forcefully in R. E. Hoover, "The Ophthalmologist's Role in New Rehabilitation Patterns," *AMA Archives of Ophthalmology*, Vol. 78, No. 5, November 1967.

²² Interview #1016, p. 6.

²³ Gerald E. Cubelli, "Some Dynamics of the Referral Process," *Rehabilitation Literature*, Vol. 31, July 1970, pp. 200-202.

²⁴ Rand Report R-1220-HEW, pp. 127-130, 221-228, 233, 257.

²⁵ E.g., James G. March and Herbert A. Simon, *Organizations*, John Wiley and Sons, New York, 1958, pp. 36-47; and Peter Blau, *The Dynamics of Bureaucracy*, University of Chicago Press, 1955, passim.

²⁶ Gideon Sjoberg, Richard Brymer, and Buford Harris, "Bureaucracy and the Lower Class," *Sociology and Social Research*, Vol. 50, April 1966, pp. 325-337.

²⁷ R-1220-HEW, pp. 94, 125, 130-131, 136, 159-163, 214-215, 232-233, 262, 265, 273-282.

scanty operational data to other executive agencies, the system gives little help to legislative decisionmakers. Lacking even crude summary information, political decisionmakers have a hard time making rational, equitable, or humane judgments about new policies and programs on behalf of a defined clientele. Even if they were to get the facts, legislators have next to no resources to analyze and interpret them.²⁸ The size and specialization of the handicapped service system works to the advantage of well-organized groups who may present only that part of the case redounding to their limited clientele's advantage. The information market is distorted and grossly imperfect at present. Direction Centers could collect and pool much of the needed information.

One desirable recourse—and this represents a major reorientation—would be to devise procedures and institutions that could examine the effects of all pertinent services on the lives of the people who receive them.

DESIRABLE CHARACTERISTICS OF A DIRECTION SERVICE

Several general characteristics can be designed into a direction service to enhance its effectiveness. There is a need to structure direction so that, consistent with the individual's and society's limited resources, the handicapped person has improved chances to become as independent as possible, and to round out his development with as many services as he can profit from. At the same time, the incentive systems that motivate agencies and professionals should be structured so as to marshal their full support behind the handicapped person and his family in their efforts to obtain the mix of services they need. Rather than an assortment of uncoordinated service agencies, many of them unknown to the handicapped person, and offering a tightly restricted range of services, the handicapped person requires some coordinated and flexible means of finding out what services are available and where to go to get the ones he needs.

Two general perspectives are to be considered in designing an improved direction service: the individual's and the system's.

Individual Design Perspective

Because the current service system is demonstrably unresponsive in important ways, it is necessary to build in counterfragmentary, counterbureaucratic, and counterspecialist structures and incentives at a localized service delivery level to insure that equitable and effective care is received. The following list of requirements summarizes how this might be accomplished.

Develop a One-Stop, General Information Service. An institution specializing in direction could answer the following types of questions for parents of handicapped children:

- Where does one obtain general help and guidance in rearing a handicapped child?

²⁸ The difficulty has been summarily treated in Donald C. Menzel, Robert S. Friedman, and Irwin Feller, *Development of a Science and Technology Capability in State Legislatures*, Institute for Research on Human Resources, University Park, Pennsylvania, June 1973, p. v: "The professionalization [specialization] of public agencies has produced, in brief, a new problem: a substantial and steadily growing imbalance, between executive and legislative capabilities to initiate, critique, and evaluate public proposals and ongoing programs. This problem is not due to inadequate expertise in state government; it is the result of the unequal and uneven distribution of existing expertise." (Italics omitted.) This is another way of stating the point we are making.

- What medical care is required and available; where is it located; how does one obtain it?
- What educational services are required and available; where are they located; how does one obtain them?
- What sensorial aids are required and available; where are they available; how does one obtain them?
- Where are counseling services available to help the family to understand the special emotional demands created by having a handicapped child?
- What vocational opportunities and services are available; where are they located; how does one obtain them?
- How much will it cost and where does one obtain financial assistance if needed, to pay for the services required by the child?
- What should be done (or not done) to encourage a handicapped child to become as independent as possible?

Demand a Multidisciplinary Effort. Such an institution must strive to be as explicitly multidisciplinary as possible to avoid undue emphasis on certain types of services, to integrate the many specialized services the client needs, and to provide a client-oriented interface with the dispensing specialists.²⁹ Experts from various disciplines with special skills in working with hearing and vision handicapped persons should be included.

Emphasize a Temporal Dynamic, Not Static, Orientation. There is a clear need to integrate the planning to meet an individual's service needs, and later to evaluate the effects of services so that changes in the child's needs are accounted for as they vary over time in response to changes in the life situation and in response to service provision.

Create Distinct Administrative Roles and Functions. A good direction service should be continually apprised of the status of all eligibility regulations and availability conditions for services from other agencies. It should maintain an active appointments process on behalf of handicapped clients, and in so doing it will generate a network of service contacts. The direction service should promote procedures for recall—for example, in the event that services become locally available or anticipated changes occur in the child's situation; and procedures for follow-up—for example, in the event the parents themselves do not or cannot obtain recommended services from other agencies.

Maintain Each Individual's Service Information. A direction service should compile and maintain records of all services each client receives including updates, service terminations, and parents' assessments of their satisfaction with the service. These records would be made available to other service providers, with confidentiality safeguards invoked as appropriate.

Foster Client Participation in the Direction Service. Active involvement by parents could at least partly relieve some of the negative feelings many of them have developed under the current system. Numerous researchers and commentators on the general subject of citizen participation offer evidence that the chance to participate can do much to alleviate people's sense of frustration and powerlessness, and perhaps a little—admittedly, not much—to win over the alienated.³⁰ This design

²⁹ R. M. Flower, H. Gofman, and L. Lawson (eds.), *Reading Disorders*, F. A. Davis, Philadelphia, 1965, makes an exceptionally strong and lucid case for a multidisciplinary approach to handicapped care and service provision. The bases of their argument are implicitly founded on the general concepts of specialization developed earlier in this chapter.

³⁰ See, for example, R. K. Yin, W. A. Lucas, P. L. Szanton, and J. A. Spindler, *Citizen Organizations: Increasing Client Control Over Services*, The Rand Corporation, R-1196-HEW, June 1973; and R. K. Yin

objective is not novel,³¹ but the direction service appears to have a particularly attractive opportunity to realize it.³²

Foster the Humane, Personal Dimension. Success for the service system can be defined in many different ways, ranging from maximizing the individual's capabilities³³ to planned dependence.³⁴ But however one defines success, it will be the greater if the system can win the child's trust and the trust of his family, and if an empathic service-provider gives enough of himself and of his time to understand *each* child and devise a personalized, comprehensive program fitted to the child's specific needs. The direction service is the best place to perform this function.³⁵

Running the direction service efficiently of course will contribute to success, but does not constitute success; efficiency should not be allowed to become an ingrown end in itself, to the detriment of personal attention to each child.

Together, these individual design characteristics for the direction service constitute a coalescent force and major supplement to the current fractionated system, in which "success" sometimes consists of shoehorning the client into a prefabricated single program instead of seeing how well the services can be made to fit the client's needs. Lawyer Thomas Gilhool, commenting on his successful class action on behalf of mentally retarded children in Pennsylvania, summarizes the distinction succinctly:

This is a case where the class must fit the child instead of the child having to fit into any class room. . . . This is a new language, a new set of facts, and it will mean a new concept of oneself by those with handicaps of any variety.³⁶

It is a concept well worth developing and one that is implementable through a direction service.

System Design Perspective

As the sheer number and complexity of agencies and professionals increase, the odds diminish that any one of them could provide for all of a handicapped client's needs. The concept of a "direction center" as a distinct social invention should

and W. A. Lucas, "Decentralization and Alienation," *Policy Sciences*, Vol. 4, September 1973, pp. 327-336. Both studies stress that increased participation of the sort envisioned here could do much to decrease the powerlessness and frustration many people feel when dealing with large and complex systems; they are not so sanguine about the likelihood of reducing alienation, a condition that appears to arise from a variety of factors not easily affected by increased participation alone.

Herbert Kaufman, "Administrative Decentralization and Political Power," *Public Administration Review*, Vol. 29, January-February 1969, pp.3-15, has commented at length about the likely and mostly undesirable societal effects of centralization.

³¹ Elliott Richardson has stressed the importance of the concept and the desirability of the objective in his "Significant Individual Participation," *Law School Record*, University of Chicago, Vol. 15, Autumn 1967; and Hans B. C. Spiegel has recorded the extent of citizen participation in a survey of federal programs in his "Citizen Participation in Federal Programs," *Journal of Voluntary Action Research*, Monograph No. 1, 1971.

³² The case for a direction service is roughly outlined in W. Wolfensberger, *Toward Citizen Advocacy for the Handicapped*, USPHS Grant HD00370, Washington, D.C., January 15, 1971.

³³ See Rand Report R-1220-HEW, Chapter 4.

³⁴ L. L. Havens, "Dependence: Definitions and Strategies," *Rehabilitation Record*, Vol. 8, March-April 1967, pp. 22-28; Secretary of Health, Education and Welfare, "Planning Guidance Memorandum—1972," February 15, 1972. The realistic point that some fraction of the handicapped population will never achieve "normal" levels of nondependence has been treated sympathetically by Leslie Gardner, "Planning for Planned Dependence?" *Special Education*, Vol. 58, March 1969, pp. 27-30.

³⁵ This is discussed in Charles B. Truax and Robert R. Carkhuff, *Toward Effective Counseling and Psychotherapy: Training and Practice*, Aldine, Chicago, 1967.

³⁶ *Los Angeles Times*, February 5, 1973, Part I, pp. 1, 11.

enable many specialized talents to be brought to bear more effectively in the service of the child and his needs.³⁷ To this end, several desirable design characteristics, discussed below, will allow the direction center to relate and interact with the existing system.³⁸

Foster Comprehensiveness of Service Scope. All types of service needs affecting the hearing or vision handicapped child must be identified and accounted for by direction service personnel. The problem is to coordinate a variety of service professions. The direction service personnel could provide outreach, diagnostic, planning, referral, and follow-up services themselves or through consultants. Traditional providers of other services—e.g., medical, special education, vocational rehabilitation, and welfare—would still provide those services. Thus, the present service system would not be circumvented or duplicated, but rather would be complemented and made more effective by the direction centers.

Serve All Hearing and Vision Handicapped Youth in the Local Region. A direction center can achieve its maximum potential only if it is located close enough to the handicapped youth's home so that he can reach it without excessive travel, and if all hearing and vision handicapped youth in the region are served without discrimination.

Concentrate on Evaluation from the Individual's Perspective. Sound evaluation of a single client's service package, and of the service system, depends on the collection of sound and complete information.

Before a child's total needs may be determined, past records must be compiled and gaps in the current package of services received must be sensed. Once an initial evaluation has been completed, a suitable list of goals (with a timetable for achieving those goals) may be developed. Once established, these goals become clues about the kinds and amounts of service needed in the short and longer terms. In the aggregate, such clues may signal needed current or future reallocations or adjustments in the overall service system. This process has been described by Knott for rehabilitation, although its application is clearly more general:

Ideally, setting of goals is accomplished in patient evaluation and re-evaluation conferences where all the professions concerned may contribute suggested goals and methods of achieving them, and even more important, where agreement can be reached on a program of unified action.³⁹

Evaluations of the system, its components, and overall performance are to be encouraged. What we have in mind was suggested by a current practice employed by several state Crippled Children's Service Directors. Over a period of time, some service providers perform more notably than others; they may have more positive medical results, work for lower fees, or generally be regarded more favorably by the parents and children. A valuable by-product of an on-going utility analysis and evaluation of all service received would be the identification of superior providers and of new and better services. Changes in the characteristics of the handicapped population could also be sensed, and therefore the need for compensating changes in the service system.

Stimulate an Active Outreach/Identification Program. As Chapter 4 demon-

³⁷ Cubelli, op. cit.

³⁸ Working from different premises and considering a vastly different assortment of program areas, Peter Drucker has developed a compatible list of general objectives for public service institutions: "Managing the Public Service Institutions," *The Public Interest*, No. 33, Fall 1973, pp. 43-60; see esp. pp. 58-60.

³⁹ Leslie W. Knott, "Evaluation Process in the Rehabilitative Program," *Med. Treatment*, Vol. 5, September 1968, pp. 693-699.

strates, the identification of handicapping conditions is not being vigorously pursued. A direction center could be an important agent in coordinating screening and case-finding activities, and insuring that follow-up procedures are instituted once a hearing or vision handicapped child is discovered.⁴⁰ Early preschool identification and service of the deaf could be an especially desirable effect of the direction centers.

Concentrate on the Practicality and Feasibility of Services and Programs. Since not all parents of hearing or vision handicapped children can be fully informed and unbiased consumers, a distinct function for a direction center would be to monitor the match between a child's realistically determined needs and his ability to benefit from services received. While the problem of under- and over-service will always be with us, it doubtless could be reduced if sufficient attention were paid to this design characteristic. It could also be reduced as good evaluation information becomes available.

Serve as a Local Spokesman for Hearing and Vision Handicapped Persons Generally and for Individual Clients Particularly. The direction center, as conceived here, would be an important focus for citizen needs and expectations. It is a place in the system where grievances may be aired—a place that does not currently exist. Specifically, a direction center could become a local "court of appeals" to which bureaucratic and other grievances could be taken, particularly if there were reason to believe that the general rules or treatment were invalid or unjust in an individual case.⁴¹ It could also become an articulate and well-informed spokesman for handicapped persons in general, in promoting changes in the supporting service system.

Reconfigure Existing Control and Incentive Systems. To attain maximum quality in the direction centers, new lines of authority and new professional identifications will probably have to be organized. In particular, a shift in traditional allegiances will be called for:

- Allegiance *not* to a currently existing professional field or specialty;
- Allegiance *not* to current programs, the people who operate them, or agencies that perpetuate them;
- Allegiance *not* to the status quo;
- Allegiance *not* to social and professional etiquette that frowns on the raising of unpopular issues;
- Allegiance to handicapped people wherever they are, and to their needs, interests, and aspirations.⁴²

To operate in this new mode, it is fairly obvious that a direction center will have to be independent of existing service agencies. One idea might be to create a line of authority and control running from the various local direction centers directly to an advisory council at a higher level of government,⁴³ which, in turn, does not report to any of the existing service agencies, but rather to the governor. Funds for the direction center would thus flow from a line in the budget separate from other services for the handicapped.

⁴⁰ W. Hoff has elaborated this point with skill and compassion. See his "Why Health Programs are not Reaching the Unresponsive in our Communities," *Public Health Reports*, Vol. 81, July 1966.

⁴¹ With respect to hearing standards, Howard House has been an advocate of the "court of appeals" concept; we are arguing that it is more general. See his "Hearing Standards—Fact or Fiction?" *Arch. Otolaryng.*, Vol. 90, August 1969, pp. 208-213.

⁴² Proposed by Benjamin C. Johnston, "Advocacy for the Handicapped," paper presented at the Fourth Southeast Regional Conference of the American Association of Workers for the Blind, July 27, 1972.

⁴³ A similar recommendation appears in New York State Committee for Children, *A Child Advocacy System in New York State*, Albany, New York, November 30, 1971. We discuss the New York creation in a following subsection.

Satisfy Existing Federal Requirements for Service Integration. A legal requirement to coordinate federal grant-in-aid programs exists in the form of the A-95 review process, a provision of Title IV of the Inter-Governmental Cooperation Act of 1968. There is no reason to assume that provisions of A-95 cannot be carried out on behalf of citizens in a target population, such as the handicapped, as well as generally throughout a geographic area. *Regional* direction centers could receive a legal boost via amendments and clarification of the basic, existing A-95 provisions. The objective of these adjustments would be to coordinate programs, but to do so directly on behalf of the individual intended service recipients. An already existing regional bias in current federal administrative practice may contribute to the implementation of direction centers; furthermore, a regional bias appears to square with the realities of the size of, and practical means of serving, the handicapped population generally.

EXISTING PARTIAL MODELS OF DIRECTION CENTERS

Many current programs are partial approximations to the design characteristics just described. The following discussion has several purposes: to show that each design characteristic is feasible; to indicate where one might wish to conduct more detailed studies and analyses to assess relative strengths and weaknesses before trying to implement features of the illustrated cases; and to confirm the appropriateness of the design characteristics themselves (for example, direction services that incorporate relatively more of the characteristics are "better" than those that incorporate fewer).

Partial models exist in many locations, because the problems of direction are general. Here, we review programs in only a sample of those locations (first in the United States, then in foreign countries). No one model, to the best of our knowledge, is complete enough to be labelled "ideal," and, hence, apt to be easily transferred and replicated. But several of them embody promising features.

The first three partial models we discuss are ambitious activities, representing three quite different strategies of implementation for our recommended direction service. In late 1971, the New York State Committee for Children proposed to Governor Rockefeller that an ambitious "Child Advocacy System" be implemented as rapidly as possible to alleviate many direction-related crises;⁴⁴ the Maryland State Department of Education, using ESEA Title VI funds, has designed and begun to implement a "Maryland State Data System for the Handicapped";⁴⁵ and the program of Regional Diagnostic, Counseling, and Service Centers for the mentally retarded of California, in operation since 1965,⁴⁶ has been widely acclaimed as a breakthrough in service provision.⁴⁷

We have selected these three activities for first presentation because individually they embody and extend the concept of direction in tangible ways, and because collectively they represent a close approximation of the direction service we recom-

⁴⁴ Ibid.

⁴⁵ Maryland State Department of Education, *Data System for the Handicapped: Toward the Implementation of the Maryland State Data System for the Handicapped*, ESEA, Title VI Proposal, March 21, 1972.

⁴⁶ *California Statutes of 1965*, AB 691, Chapter 1242, pp. 3106-3108.

⁴⁷ In a covering letter introducing a brochure popularizing the program and explaining the legislation as amended in 1971, Governor Ronald Reagan observed about the "Lanterman Mental Retardation Services Act": "That progressive legislation provides us with a dynamic framework on which we shall build a comprehensive system to assure that the mentally retarded develop to the fullest extent of which they are capable."

ment on a national basis. We believe that most of our direction design characteristics could be realized by a selective, thoughtful, and careful amalgamation of the better features of these examples.

New York State's "Child Advocacy" System

The New York State Committee for Children has devised a highly interesting plan that is still in the proposal stage. Reporting to the Governor in November 1971, the Committee recommended the creation of a State Child Advisory Commission and local advocacy councils that "would have the power and the duty to review present services to children, to suggest changes and to represent the interests of children."⁴⁸

This concept included a state-level commission, "independent of existing departments of state government and able, therefore, to keep as its central responsibility a concern for the welfare of all children."⁴⁹ Locally, the intent of the proposed system would be carried out by "advocacy councils with a responsibility for all children in their localities, with the power to gather information, respond to felt needs, and recommend changes as indicated."⁵⁰

Costs were intended to be minimized by manning the local councils with voluntary personnel. The recommended budget for the first year of operation of the State Commission was \$950,000, some \$350,000 of which was earmarked for staff support and travel, and the balance "to be used to support the development of a number of pilot programs at the local advocacy council level."⁵¹

The composition of the State Commission was recommended to be 100 members, from a variety of prescribed professions, socioeconomic strata, and age categories. Parents would constitute at least a 51 percent majority but no more than 70 percent. Commissioners would serve by gubernatorial appointment for terms ranging from one to three years. The State Commission itself would report directly to the Governor on matters of policy and operational significance affecting the lives of children in New York.

The local advocacy councils are intended to be major points of citizen access for direction service, and would report directly to the State Commission on their operations and findings. It was hoped that compiling legal compendia and rosters of locally available services would satisfy information deficiencies, and that review, evaluation, and fact-finding would improve performance. Various specific duties and powers are also spelled out, which approximate some of our direction service design characteristics⁵²

The Child Advocacy System concept is interesting and important for several reasons:

- It recognizes the need to complement the existing system, and to do so with clear lines of authority and control running directly to the Governor, rather than running through the existing service agencies.

⁴⁸ New York State Committee for Children, p. 1.

⁴⁹ Ibid.

⁵⁰ Ibid., pp. 1-2.

⁵¹ Ibid., p. 8. Also (p. 2), "the Commission shall seek federal funds as they become available."

⁵² In a recent, sensation-provoking report, "Juvenile Injustice," seven present and former judges and a number of senior administrators of the New York Family Court charged that the system was failing to such an extent that "changes must be made before yet another generation of children is destroyed." Peter Kihss, "Children's Justice Called a Failure by Judicial Panel," *New York Times*, October 29, 1973, pp. 1, 25. This represents yet another manifestation of the general problem, but this time as it appears in the treatment of children by the judicial system.

- It stresses the perspective of the individual and his family, not that of the existing system or its specialized constituents.
- It values the importance of information as a resource to be used in a two-way communication process: direction to the parents and feedbacks about performance to those most generally responsible for that performance.

But,

- Final implementation design of the general concept and system is not complete. Governor Rockefeller's letter of receipt for the report contains the closing line, "I look forward to seeing additional details of the child advocacy proposal as it is further refined."⁵³

Maryland State Data System for the Handicapped

Maryland officials have begun implementation of a state data system for the handicapped that collects and centralizes information from the state's current scattered programs. They have generated an important piece of an emerging direction service, but the "piece" suffers from want of being integrated into a general concept and overall direction system, such as the one proposed in New York.

The technical problems associated with any large, information-based activity, such as direction, are certainly many and difficult; however, they are manageable if due consideration is given to system design and early implementation.⁵⁴

A technically adequate "Data System for the Handicapped" (DSH) is being implemented in Maryland and reportedly has over 70,000 children registered.⁵⁵ The Maryland proposal for this data system requesting early implementation funding called for \$123,144 and contains an impressive list of reasons and anticipated benefits for the system,⁵⁶ most of which have been generalized in our direction design characteristics. Among the striking facts already discovered during implementation is the finding that the average lag time between the identification of a handicap and the commencement of services is excessively long: 500 days for the hearing impaired and 131 days for any handicapped child requiring residential school services. It was also found that of the handicapped children known and registered in the DSH, approximately 7000 were identified but not yet served.⁵⁷

An issue with the DSH, as with all public data systems, relates to privacy safeguards.⁵⁸ It is a problem that threatens both present and future efforts to manage information on and for the handicapped; however, ways to resolve the problem are presented in the recently completed Report of the Secretary's Advisory Committee on Automated Personal Data Systems,⁵⁹ compiled for the Secretary of HEW. It would be unfortunate if the inroads made in Maryland toward resolving the technical information problems of direction were subverted for nontechnical issues and

⁵³ Letter, Governor Nelson A. Rockefeller to Dr. Alan D. Miller, April 4, 1972.

⁵⁴ Besides the Deaf-Blind Centers Information System reported on later in this chapter, the following related development is notable: C. Vallbona et al., "An On-line Computer System for a Rehabilitation Hospital," *Methods of Information Medicine*, Vol. 7, January 1968; for a less technical description of this system, see Nancy De Sanders, "Computer's Basic Plans Help Doctors Initiate Rehabilitation Regimen," *Modern Hospital*, Vol. 113, November 1969, pp. 97-100.

⁵⁵ *Education Daily*, Vol. 6, No. 200, October 18, 1973.

⁵⁶ Maryland State Department of Education, op. cit., pp. 16, 23.

⁵⁷ *Education Daily*, same issue, p. 3.

⁵⁸ Ibid.

⁵⁹ *Records, Computers, and the Rights of Citizens*, DHEW/OS Report No. 73-94, 1700-00-116, Washington, D.C., 1973. A summary of this live and important issue is contained in R. E. Cohen, "Justice

reasons that are in principle resolvable. Another problem noted by those responsible for the Maryland system is the reluctance of some parents to have their child labelled as "handicapped." Data forms and the official name of the system are being changed to alleviate this problem.

California's Regional Centers ⁶⁰

In 1963, the California State Assembly created a subcommittee to investigate the problems confronting the mentally retarded generally and to make legislative recommendations. It did so in response to many fundamental questions about the care provided to the mentally retarded in California,⁶¹ and before deciding whether to increase the state's investment in residential mental institutions. In 1965, the subcommittee reported its findings—and they were startling:

- The mental hospital represented the only major means for the mentally retarded to receive state aid.
- Long waiting lists impeded even this one option.
- These people do not need all of a hospital's services but, in the "all or nothing" situation then prevailing, they often got them anyway.
- Little or no help of any kind was locally available from the public service sector.⁶²

The subcommittee recommended the creation of regional diagnosis, counseling, and service centers for the mentally retarded—a recommendation contained in Assembly Bill 691, 1965, truly a landmark piece of legislation.⁶³

The "regional centers" thereby created were to provide the following services:

- Diagnosis;
- Counseling on a continuing basis;
- Provision of state funds to vendors of services, when, lacking such services, the only recourse would be institutionalization;
- Maintenance of a registry and individual case records;
- Systematic follow-up and reactivation of cases if needed;
- Assistance in state hospital placement when necessary;
- Education of the public about needs and capabilities of the handicapped;
- Staffing according to standards set by the State Department of Public Health.

The regional centers idea started in 1966 with two pilot projects, one in Los Angeles and one in San Francisco, operating on a budget of some \$600,000. By FY 1974 it had grown to an over-all \$22.2 million proposition, with 14 centers operating

Report/Nixon Administration Weighs Restrictions on Use of Criminal History Data Banks," *The National Journal*, October 27, 1973, pp. 1599-1607.

⁶⁰ Documentation describing the regional centers is complete and clearly presented. See, e.g., Edgar W. Pye, *California's Regional Centers: Gateway to Services for the Retarded*, Bureau of Mental Retardation Services, State Department of Public Health, Berkeley, Calif., 1970; State Human Relations Agency, *Lanterman Mental Retardation Services Act*, Sacramento, Calif., 1971; and "Lanterman Mental Retardation Services Act," *Liaison*, Vol. 2, No. 2, March 1973 (Sacramento, Calif.). Performance data are not as complete or available.

⁶¹ One source specifically notes the importance of the creation of the President's Panel on Mental Retardation in 1962 as a stimulus for California to look more carefully at problems confronting its mentally retarded. Pye, *op. cit.*, p. 1.

⁶² Report of the Assembly Committee on Ways and Means, Subcommittee on Mental Health Services, State of California, Sacramento, Calif., 1965.

⁶³ *California Statutes of 1965*, AB 691, Chapter 1242, pp. 3106-3108 (cited provisions at p. 3107).

throughout the State and a small additional number being discussed.⁶⁴ Of course, this budget is not all for direction, as many other types of services are purchased.

Regional centers have been embedded in an institutional framework that in 1971 include 13 Mental Retardation Program Area Planning Boards, responsible for planning and coordinating all mental retardation services in their respective planning areas⁶⁵ and representing parents (25 percent), professionals (50 percent), and representatives of the general public (25 percent) in each of its 14-to-19-member bodies.⁶⁶ At the State level there is a Mental Retardation Program Advisory Board, responsible for developing a statewide plan based on county and area proposals and for advising the State executive and legislative bodies about the status and needs of the mentally retarded throughout the state.⁶⁷ Budgetary and primary responsibility for implementing the plan rests with the Human Relations Agency, its Office of Mental Retardation, and other of their subordinate activities.

The regional centers themselves are staffed somewhat differently in each situation, reflecting local needs and the availability of personnel; however, the staff and the caseload of the Golden Gate Regional Center in San Francisco are at least illustrative. In addition to a director and associate director, it includes a senior staff physician, a public health nurse, a chief of administrative services, a chief counselor, a supervisory counselor, and ten staff counselors "... whose professional training is in social work. And the counselors are stationed in the communities for which we relate our services."⁶⁸ The active caseload reported on January 1, 1970, was 450, of whom 230 were receiving services provided and paid for, in whole or part, by the regional center.⁶⁹

The regional centers strive to follow a "Case Management Flow Process," the details of which were described for us by Dr. Charles Gardipee, Chief of the California Bureau of Mental Retardation Services, in the following terms:

- *Screening*, with the option to refer the client out of the regional center to some other more appropriate service, if required.
- *Intake interview*, with an option to refer out. At this point a complete information file is collected from all public sources and, to the greatest extent possible, private ones as well.
- *Initial case staffing*, where information developed in the intake interview is evaluated by a committee or board of the regional center including social workers, doctors, and medical administrators.
- *Case staffing* and creation of a plan for the handicapped client, tailored to his needs to the extent services are locally available.

⁶⁴ In recognition of his central and faithful role in the invention and implementation of the regional centers, new and expanded legislation bore the name of Frank Lanterman, Assemblyman, 47th District, Pasadena: "Lanterman Mental Retardation Services Act of 1969," *California Statutes of 1969*, AB 225, Chapter 1594.

⁶⁵ Lucian B. Vandegrift, Secretary of Human Relations, State of California, *Mental Retardation Program: Suggested Procedure for Area Planning*, Human Relations Agency, Sacramento, Calif., July 15, 1970.

⁶⁶ *Lanterman Mental Retardation Services Act*, p. 9. These people must also reside within the planning area.

⁶⁷ The Board's composition is defined by terms of California's AB 225 of 1969 and includes voting members: two from the public at large, a parent of a mentally retarded child who is a patient in a state hospital, a parent of a mentally retarded child who is not in a state hospital, a county supervisor, and one member from each of the following professions: medicine, psychology, social work, nursing, education, and law. Appointments to the Board are shared on a formula basis by the Governor, the Chairman of the Senate Rules Committee, and the Speaker of the Assembly. Service is without material compensation.

⁶⁸ Pye, op. cit., p. 7.

⁶⁹ *Ibid.*, p. 9. The 450 figure is static and does not represent an annual figure.

- *Execution* of the plan.
- *Review and evaluation* of the plan and the client's progress based on the criteria established during the case staffing and planning phase.⁷⁰

The average annual professional costs for each regional center are estimated to be approximately \$250,000 for purposes of his analysis, although in practice this estimated average probably varies considerably (see Table 3.2). The State Budget for FY 1972 allotted the following funds to these regional-center-related activities: case funding and identification, \$1.6 million; case evaluation, \$3.9 million; and case management, \$1.8 million; for a total of \$7.3 million. A simple average for each functional activity per center funded in FY 1972 would then be \$123,000; \$300,000; and \$138,000, respectively, or a total of about \$560,000 per center per year. Since this program is in its initial rapid expansion phase with attendant initial staffing and facility costs and the caseload during that phase consists of persons requiring, primarily, initial intake and direction, meaningful long-term average annual costs per case are not available.

Table 3.2

ESTIMATED PROFESSIONAL PERSONNEL COSTS PER ANNUM
FOR CALIFORNIA REGIONAL CENTERS

Position	Cost Per Center
Director (M.D.)	\$ 30,000
Associate Director	20,000
Staff Physician	25,000
Public Health Nurse	15,000
Chief, Administrative Services	15,000
Chief Counselor	20,000
Supervisory Counselor	18,000
Staff Counselors: 10, at \$12,000	<u>120,000</u>
Total	\$263,000

SOURCE: Interview with Dr. Charles Gardipee, March 6, 1972.

NOTE: The total shown does not include overhead charges and supporting staff. The more inclusive State Budget estimates provide for a total of \$560,000 per year per center.

Population characteristics for each of the regional centers are shown in Fig. 3.1. Summary statistics for the program's five-year history are shown in Table 3.3 and Fig. 3.2. Note that for the California regional centers there is a great deal of variation in total catchment size (from 185,000 in Mendocino-Humboldt-Del Norte to 7.034 million in Los Angeles) and in travel times to a regional center. The extreme variation represented by Los Angeles has resulted in the planned addition of two or perhaps three additional regional centers for the greater Los Angeles basin. Travel times are not directly reflected in the state budget.

For completing a thorough evaluation of the California regional centers, these

⁷⁰ Interview, March 6, 1972.

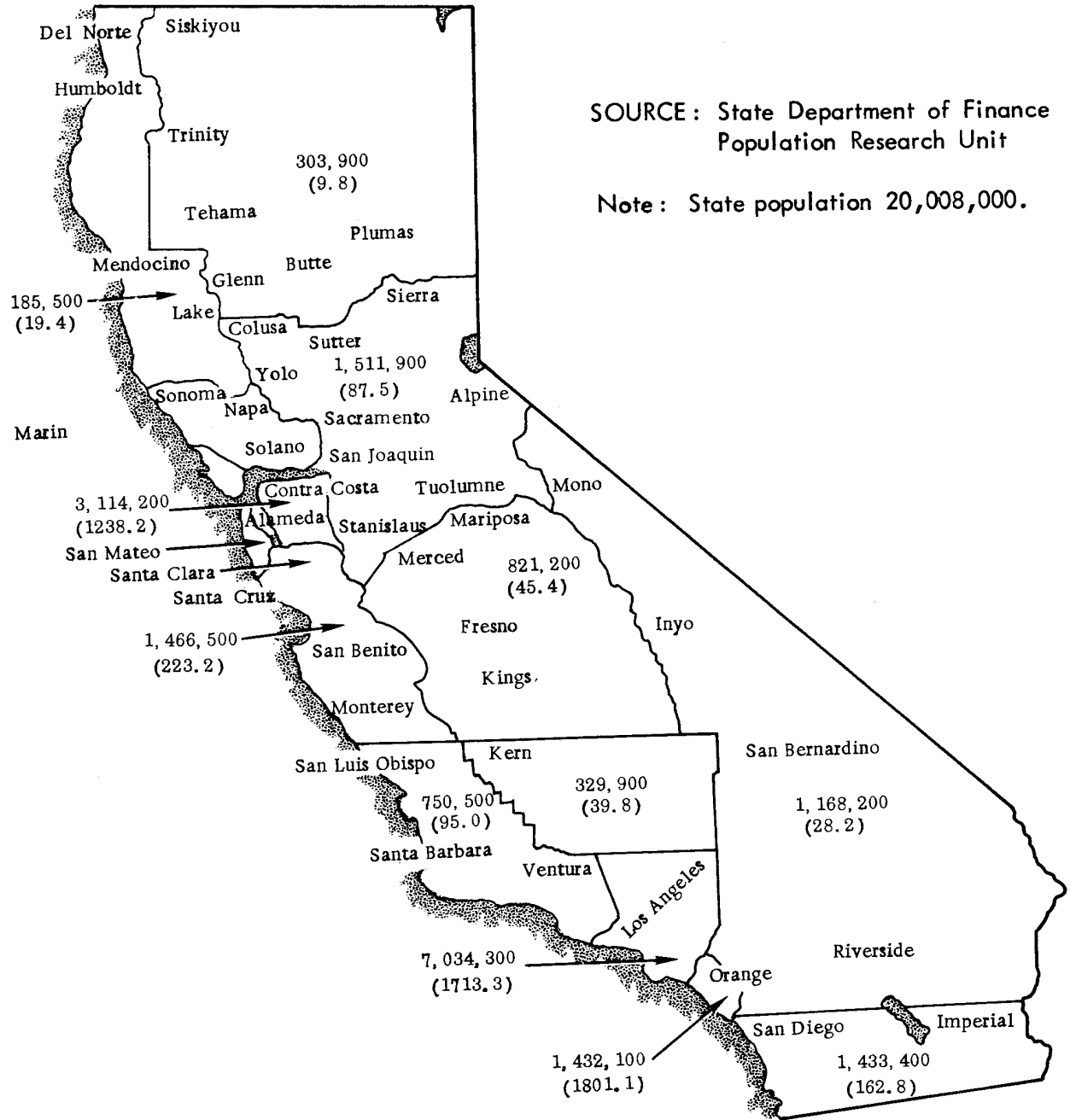


Fig. 3.1—California Regional Center program, 1971: area populations and population densities (persons per square mile)

Table 3.3

CALIFORNIA REGIONAL CENTER PROGRAM FROM INCEPTION THROUGH DECEMBER 31, 1971

Number of Regional Centers, December 1971		
Fully operational		9
Initiating services		1
Awaiting final approval of contracts		3
Statistics (last quarter of calendar year 1971, estimated)		
Total referrals and requests for assistance (1/66-12/71)	25,000	
Total intake processes initiated (1/66-12/71)	9,800	
Caseload, December 31, 1971	6,000	
(Note: this does not include some 500 individuals and/or families who, each month, receive some type of Regional Center assistance prior to initiation of the intake process.)		
Inactive cases, December 31, 1971	880	
Closed cases (deceased, diagnosed not mentally retarded)	330	
Purchase of services, December 1971		
Individuals and/or families receiving purchased services	2,000	
Clients in residential placements (subtotal of above)	750	
Total budgets for Regional Center Program ^a		
Fiscal Year 1971-1972	\$10,252,272	
Fiscal Year 1972-1973	\$14,367,000	
Costs per case-month of care (1970-1971)		
Purchase of services	\$ 78	% 51
Direct Center services		
(costs attributable to diagnosis and counseling)	59	39
Regional Center administrative costs	13	9
Bureau administrative costs	2	1
Total	\$152	100%

SOURCE: California State Department of Finance.

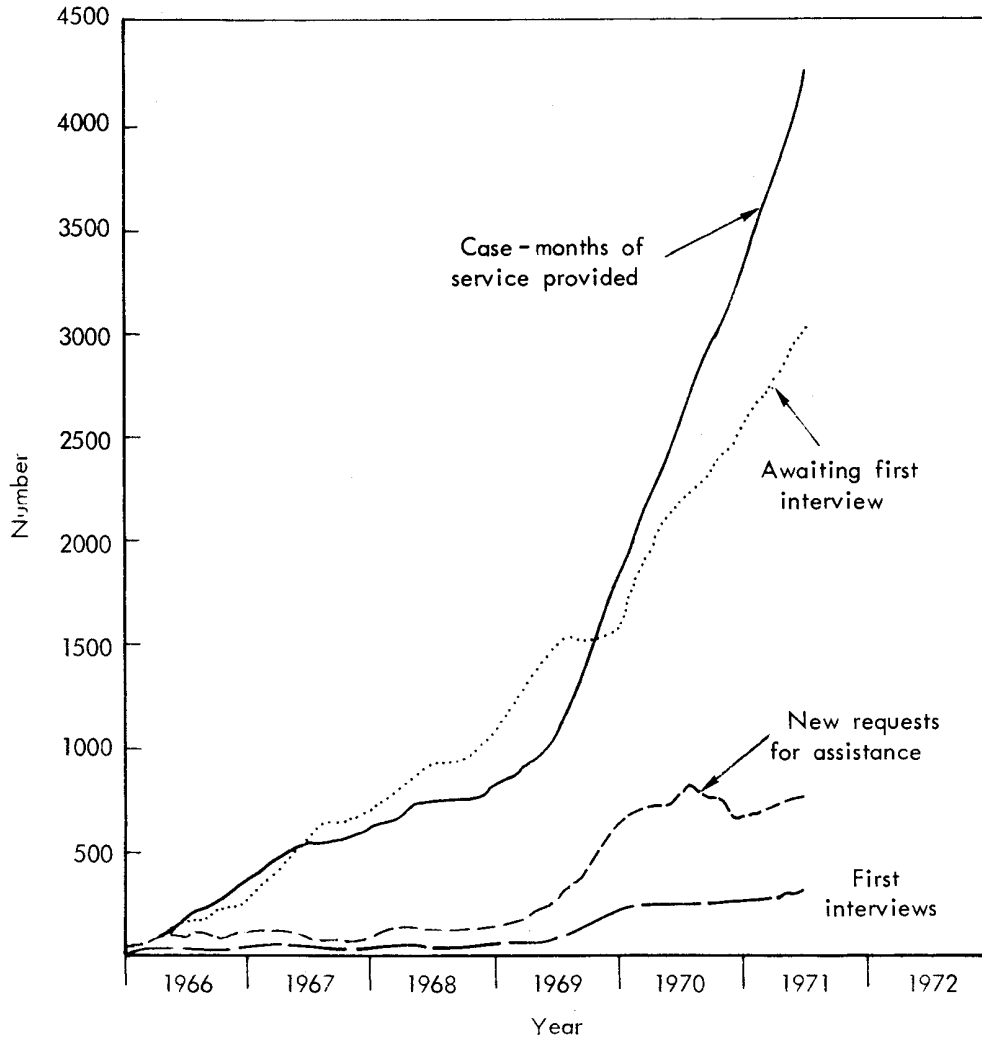
^a\$22.2 million in Fiscal Year 1974.

data are plainly unsatisfactory,⁷¹ but they are instructive for the purpose of extending the concept of the regional center to a national scale.

The regional centers program has many positive aspects. The families we interviewed who were fortunate enough to make it through the waiting lists and received regional center service uniformly praised the service and the center's personnel; the physicians we contacted were generally favorably disposed to it on the grounds that the centers had access to information that they did not and that was of great use to the families; and state public health administrators of the program were also supportive. The centers are beset, however, by several recognized and persistent problems that bear careful examination although we note them here only in summary fashion:

- Regional centers have some power over state mental institutions, and this can lead to direct conflict. Under the regional center concept, the state hospital is only one of many service-vendors that may be planned for the individual child.
- Interaction with the so-called "Short-Doyle" program (to provide a local alternative to the mental hospitals) has had the effect of rapidly loading the regional

⁷¹ As of this writing, we know of (but we were not given access to) a report compiled by the staff of the State Department of Finance, examining Regional Centers in detail. If made publicly available, this report should satisfy much of this need.



Source: California State Department of Finance

Fig. 3.2—California Regional Center program (5-month moving averages)

centers with clients. The shift from state institutional to local care has been rapid.

- Animosity connected with the hospital closure issue has spilled over to the regional centers program, pitting rural legislators (who stand to lose important and nonfungible local industries), psychiatric technicians (who stand to lose their jobs), and other miscellaneous groups, against the regional center concept and practice.
- Local problems have been noted, particularly in the early stages of locating and implementing the regional centers: zoning is frequently used to prevent the location of centers in incorporated areas, funding for facilities is sometimes hard

to obtain or obtained only at premium rates, and community acceptance of mentally handicapped people in their midst is not always positive.

- Waiting times tend to be long. Not only has deinstitutionalization contributed to this, but the extent of unmet demand was not well estimated, in the following sense: if one has a real but "marginal" problem, travel to a distant facility for care becomes a seriously inhibiting consideration; however, when the facility is relatively closer at hand, the travel constraint lessens and service is demanded.
- Local service facilities have not been created or expanded as fast as the demand for service.
- Follow-up and evaluation (noted in the "Case Management Flow Process") are very hard to carry out in practice. There are no well-known criteria and a variety of needed, specialized services is not always locally available; i.e., if a service received is not appropriate or satisfactory, there is often no readily accessible alternative.
- Given all of these systemic features, it is to be expected that the regional centers have not been able to realize their full potential to case-find, coordinate, and evaluate at the individual level.
- Because the regional center is structured within the existing service bureaucracy in California, it is susceptible to pressures to favor one or another existing type of service program, rather than being independent and fully child-centered.
- The regional centers rely very heavily upon social workers to execute the program at the client level. Social workers have many commendable skills; however, one should be alert to insure that social worker norms and modes of operation do not become the norms and modes of operation for the regional centers. One manifestation of this would be a "style" characterized by long-term case management (a task of the Department of Social Welfare) and not one of short-term case-finding, coordination, and evaluation (relatively "unique" functions not presently done by any line agency as a main order of business).

Direction is an important service that has many unique features not routinely performed by existing agencies. To the extent that direction is not recognized as a different concept and service, and to the extent that direction is attempted within the existing, unreconstituted bureaucratic framework, one would expect limitations of its full realization and potential. The need for new, clear lines of authority and control is evident in this case (a need explicitly recognized in the foregoing New York State proposal).

Deaf-Blind Centers

As a result of two separate pieces of legislation passed in the aftermath of the rubella epidemic of 1963-65,⁷² Deaf-Blind Centers were mandated and translated into policies and programs by the U.S. Office of Education.⁷³ The Deaf-Blind Regional Center program has many desirable features—prototypical "lessons learned" for our proposed regional direction center concept.

Basically, the Deaf-Blind Centers were designed to provide the following services: comprehensive diagnostic and evaluative services; programs for adjustment, orientation, and education, integrating all necessary professional and allied services; effective consultative services for parents, teachers, and others, to enable them

⁷² P.L. 90-247, January 2, 1968; and P.L. 91-230, April 13, 1970.

⁷³ U.S. Office of Education, *Policies and Procedures, Centers, and Services for Deaf-Blind Children, ESEA, Title VI, Part C*, April 1969.

to play a direct role in the lives of children, and to assist in their adjustment, orientation, and education.⁷⁴

Because they are intended to provide a full range of services to a severely handicapped subset of the total handicapped population, the Deaf-Blind Centers do not meet many of the design objectives for a purely direction-oriented service. This is not to say that Deaf-Blind Centers are not worthwhile or that they do not provide much needed services; it is to say that because a choice has been made to serve a very special and quite small population, it has been possible to include within the single institution the delivery of a full range of services. Were the choice made to serve a larger group of handicapped children, as we propose in the direction center concept, then *full provision* of services within the same institution would probably not be feasible, either because the number of clients would be too large or because too many centers would be required.

In a study of the Deaf-Blind Centers from an information system design perspective, EXOTECH Systems, in June 1971, provided some valuable ideas for consideration in the proposed direction center concept. According to EXOTECH, information about this most severely handicapped subset of the total population was "by any standard poor in quantity and low in quality,"⁷⁵ and the report detailed what might be done to improve matters on both scores. The partially implemented, prototypical DBCIS (Deaf-Blind Center Information System) that EXOTECH selected was in some senses a good and reasonable choice. The deaf-blind population is small and not too difficult to identify (about 5000 deaf-blind children are known to exist in the total population). The great complexity of the problems facing a deaf-blind child⁷⁶ actually had some positive effects for the information system. If an accounting, registry, and direction system could be built to serve the deaf-blind, then it should be feasible to extend the design to other handicapping conditions if problems associated with increasing the scale of the system can be solved. There is much truth in the EXOTECH study's concluding remark that, "Taken as a whole, the Deaf-Blind Center Information System will serve as a model for application to the entire field of the handicapped."

One reservation about simply transferring and expanding the Deaf-Blind Centers, however, is that as institutions, they are at once both too specialized *and* too generalized to satisfy the design objectives set out for a direction service. Deaf-Blind Centers are narrowly focused on the special needs of a limited subgroup, and they provide a general range of services, of which direction is only one of the less important (relatively speaking). In all likelihood the Deaf-Blind Center concept would therefore be infeasible if scaled up from serving a national population of about 5000 to serving one close to 10 million (the gross estimate of total handicapped children).

Because direction is a neglected but vital service, we are prompted to concentrate on procedures for improvement. The DBCIS is one such procedure, and its

⁷⁴ Section 622, P.L. 91-230, "Education of the Handicapped Act."

⁷⁵ EXOTECH Systems, Inc., *An Information System for Regional Centers for Services to Deaf-Blind Children*, BEH/OE/DHEW, Contract No. OEC-0-70-4923, Washington, D.C., June 30, 1971, p. xiv.

⁷⁶ The following is a mere sample of the extensive literature: E. F. Cicenia et al., "The Blind Child with Multiple Handicaps: A Challenge," *International Journal for the Education of the Blind*, May 1965, pp. 105-112; A. Kaye, "The Multiple Handicapped Child: A Challenge to Programming," *Special Education Review*, Vol. 20, 1963, pp. 1-8; H. R. Myklebust, *The Deaf-Blind Child*, Perkins School for the Blind, Watertown, Mass., 1956; and two reports on progress achieved in California's various programs for the deaf-blind: Berthold Lowenfeld, *Report on Multihandicapped Blind and Deaf-Blind Children in California*, California State Department of Education, Division of Special Schools and Services, Sacramento, May 1968; and Laurice S. Jenkins, *Follow-up Study on the First Annual Deaf-Blind Institute*, California School for the Blind, Berkeley, 1972.

adaptation and incorporation into the proposed Regional Direction Center appears to be a relatively effective way to satisfy several of our design objectives.

Young Adult Institute and Workshop of New York

Since 1957, the Young Adult Institute and Workshop of New York has provided the mentally retarded and other young adult handicapped with preemployment training, which the Institute calls "Adjustment Counseling."⁷⁷ While the program is mainly aimed at vocational placement and job preparation, its information content is of more general interest. Social, communicative, and employment skills are taught to ease the transition into the "normal" community.⁷⁸ However, the most interesting aspect of the program for our purposes is the extensive network of service providers and potential employers maintained by Institute staff. The demonstrated success rates of the program attest to the importance of such specialized information for a limited range of purposes—in this case, placement. It would be valuable to expand the concept and practice into more general application.

New York University Deafness Research and Training Center

Using the existing facilities of New York University, the Deafness Research and Training Center employs a multidisciplinary team to expand the menu of vocational services usually available to the deaf. This effort has been labelled the "Community Service Delivery Model," whose stated purpose is to develop, within the deaf community, "sophistication . . . as to the acquisition of social services . . . [and] competence in community agencies for serving deaf people."⁷⁹ To accomplish these objectives, the CSDM strives to make the community's existing services work to the best advantage of the deaf. Service responsibility is primarily left to others, while the CSDM is oriented toward referral and guidance of its clientele and toward educating the community at large about the needs and capabilities of the deaf.

While it is still too early to assess the outcomes of this effort, since it has only recently been implemented, many of its elements appear to satisfy the design characteristics we have laid out for a direction service. Before the needed assessment is carried out, however, it is appropriate to caution would-be emulators on several possibly troublesome features of the CSDM: it is located within a university and hence lies outside the political mainstream; it is a modest operation, from all indications; and it appears to have a decided research bias. All of these aspects should be considered seriously before one attempts to reproduce the model on a wholesale basis elsewhere.

Comprehensive Vocational Rehabilitation Programs

As a result of 1958 amendments to the Vocational Rehabilitation Act, several feasibility studies were conducted to determine whether the severely educationally limited deaf (those reading at a third-grade level or less) could be integrated into the community if supported by general purpose rehabilitation centers oriented to pro-

⁷⁷ Thomas-Robert Ames, "Program Profiles: A Program for Transition to Independence," *Mental Retardation*, Vol. 8, April 1970, pp. 49-51.

⁷⁸ B. Macleech et al., *An Exploration of the Advisability of Developing a Research and Demonstration Project Concerned with Elevating the Readiness for Vocational Rehabilitation of Multiply-Handicapped Young Adults*, Young Adult Institute and Workshop, Inc., New York, 1966.

⁷⁹ Frank Bowe et al., "Delivery of Community Services to Deaf Persons," *Journal of Rehabilitation of the Deaf*, July 1973, pp. 15-29.

viding a comprehensive range of adjustment and guidance services instead of being limited to vocationally related services.

Some of the results of these feasibility studies were encouraging. The design objectives of comprehensive, multidisciplinary, and personalized service provision operated to good effect. Likewise, it proved meritorious to have a single point of access through which a variety of services could be matched with the specialized needs of these seriously limited people.⁸⁰

Family Counseling for the Adult Deaf

Short-term counseling to help the deaf adult with his special problems (including diagnostics, translator services, family counseling, placement assistance, and so forth) has been shown to be promising in the three or four limited applications where it has been tried.⁸¹ The main message from all these applications is that the marginal utility of information about the availability of needed services is high, but the cost of providing that information is not. The principle is fundamental to the general concept of direction.

San Francisco Speech and Hearing Center

A well-known article by Donald R. Calvert and Suzanna Baltzer⁸² embodies some creative though somewhat limited fragments of the direction design. Concentrating on deaf preschoolers, it was demonstrated that a management program stressing "normalization" had some noticeable payoffs for the children's development and achievement. Professionals from the Speech and Hearing Center periodically visited the children's homes to evaluate their needs and then to match those needs with the capabilities of the Center and of other agencies that cooperated with the Center in providing additional services. The effort was multidisciplinary, professional, and essentially one-stop for those parents fortunate enough to benefit from the program. Furthermore, the benefits of preschool education for the deaf were "built into" the program from the start.

The small size of the preschool deaf population in the immediate area necessitated enlarging the catchment area to include northern and central California, Nevada, and southern Oregon. The resulting distances, travel time, and displacement from the family in those cases where children had to come to the Center for medical treatment must count as less than desirable features of an otherwise interesting program.⁸³

Brookline Early Education Project (BEEP)

Heralded as "the nation's first major school-based program to provide compre-

⁸⁰ C. A. Lawrence and G. M. Vescovi, *Deaf Adults in New England: An Exploratory Service Program*, SRS/DHEW, Final Report RD-1516-S, Washington, D.C., 1967; and S. N. Hurwitz, *Habilitation of Deaf Young Adults*, SRS/DHEW, Final Report RD-1804-S, Washington, D.C., 1971.

⁸¹ R. Falberg, "Community Services for Deaf People in Kansas City: A Description and Report," *Journal of Rehabilitation of the Deaf*, Vol. 3, October 1969, pp. 42-62; W. A. Ethridge, "Community Referral Sources," *ibid.*, July 1969, pp. 103-111; and J. Kane and C. Shafer, *Personal and Family Counseling Services for the Adult Deaf*, DHEW, Final Report RD-2560-S, Washington, D.C., 1968.

⁸² "Home Management in a Comprehensive Preschool Program for Hearing Impaired Children," *Exceptional Children*, Vol. 34, December 1967, pp. 253-258.

⁸³ Other problems noted included the Center's dependence on "soft" money; the fact that there were insufficient numbers of professionals trained to deal with preschoolers; and that there were few standards to rely on in teaching the very young deaf.

hensive educational and health services to children during infancy and the early years of life," BEEP is an ambitious program designed to capitalize on the mother as teacher and constant observer of her child.⁸⁴ The implicit assumption underlying much of the thinking is that the parent is an underused resource and with training and guidance could do much to educate and protect the health of the child. For our purposes, the most interesting aspect of BEEP is that it will have a referral service to help the parents find specialized medical care, and a provision to insure that the handicapped within BEEP's otherwise normal population will be followed up once they are identified. The project is funded privately by the Carnegie Corporation and the Johnson Foundation.

The project is far more elaborate and ambitious than the direction service we are proposing. It is commendable for its intention to track *all* children throughout the preschool years to promote their intellectual growth and insure that any handicaps are discovered promptly.

American Foundation for the Blind: Pilot Projects

Two pilot projects undertaken on the initiative of the American Foundation for the Blind are being conducted on behalf of preschool visually impaired children in Minnesota and New Hampshire. Their basic purpose closely resembles the direction center concept, in that they are exploring ways to coordinate local services on behalf of the handicapped child. The pilot projects may be followed by demonstration models in other areas of the country.

Judging solely by the size of the preschool visually impaired population, it would seem that size or scale difficulties would prevent such a scheme from providing sufficiently numerous or diverse services if a small catchment area is used, and that, on the other hand, an overly large catchment area would also impede the effort just as it has somewhat reduced the effectiveness of direction services for preschool hearing impaired in the San Francisco Center and in the Deaf-Blind Centers nationally. Direction, to repeat the theme, is a universally needed service whose fullest potential will be realized only when it is offered to all handicapped children, no matter what their condition.

Iowa: Community Service Centers

The State of Iowa, which has far better than average identification rates for the multiply handicapped,⁸⁵ has recently planned Community Service Centers for matching the handicapped children with locally available services. As the project is still in the design and preliminary implementation stages, little else is known about it, although it seems to be a step in the right direction. Certainly, given the importance of direction, this project deserves careful scrutiny.⁸⁶

⁸⁴ *Education Daily*, March 9, 1973, pp. 5-6

⁸⁵ Rand Report R-1220-HEW, pp. 189, 192.

⁸⁶ J. C. MacQueen et al., *Planning Comprehensive Services for Handicapped Children and Youth*, Iowa State Services for Crippled Children, Iowa City, Iowa, April 1972. From the simple inspection of the meager performance data we have been able to assemble, Iowa appears to have done well for its handicapped children in general. Whether or not this is truly the case, and why it should be so, are the kinds of questions that should be routinely raised and resolved at the federal level. If officials are doing something "right" in Iowa (or anywhere else), there is even more reason to investigate than if it is suspected that performance is not up to par.

Pennsylvania: Commonwealth Child Development Committee

The Governor of Pennsylvania is attacking the problem from another direction. By virtue of his Executive Order No. 35, a Commonwealth Child Development Committee was established to oversee and coordinate the "merger of all federal funding for medical problems of children into one agency, with sufficient capacity to conduct cost analyses and impact evaluation of programs."⁸⁷ As we shall point out in the recommendations portion of this chapter, it is critically important that there be some recognized authority outside of the existing chain of bureaucratic command to which the proposed Regional Direction Centers may report. In principle, the Commonwealth Child Development Committee, with an expanded and clarified charter, could serve this purpose quite well.

Satellite Facilities

To anticipate a possible objection to the creation of Regional Direction Centers—that they may entail excessive investment in plant—it seems useful to note here that, unlike a hospital or formal educational facility, a direction center requires only minimal, relatively unspecialized, and unadorned space.

The concept of satellite facilities, although not new, may be relevant in this case. Satellites have been shown to increase service demand by lessening the geographic constraint through the imaginative use of a variety of small, cheap, flexible, and sometimes mobile facilities.⁸⁸ Interesting examples include building space within public housing units, and even surplus firehouses.⁸⁹

Many of these examples confirm that small size and low overhead cost are often an advantage in the delivery of information-laden services such as referral, planning, scheduling, and follow-through. A smaller setting, with fewer clients and a smaller staff, can make scheduling easier, shorten waiting times, and enable people to get more thorough individual attention.⁹⁰

Observations on Promising Partial Models

In practice, direction is at best a primitively developed and poorly understood concept and service. While the foregoing examples embody many attractive and interesting features, they remain only scattered fragments of the larger and more inclusive system by our direction design characteristics. The following summarizes a few of our observations:

- Direction is in a primitive state, although the need for it is acknowledged in the prototypes and experiments reviewed.
- Data systems—stressing both operational information and information about the local context that could be used by service recipients—are virtually nonexistent.

⁸⁷ March 30, 1972.

⁸⁸ Most of the literature on this subject is thoroughly surveyed in J. R. Lave and S. Leinhardt, "The Delivery of Ambulatory Care to the Poor: A Literature Review," in William Cooper (ed.), "Urban Issues II," Special Supplement to *Management Science*, Vol. 19, No. 4, December 1972. An early statement of the satellite concept that gained some attention is Jerry A. Solon et al., "Patterns of Medical Care: A Hospital's Outpatients," *American Journal of Public Health*, Vol. 50, December 1960, pp. 1905-1913; this piece is cited to remind the reader that these ideas are not new, only pregnant.

⁸⁹ "Physician's Assistant: Medicine Acts to Meet Manpower Need," *Dental Survey: Journal of Dental Practice*, April 1969; M. I. Levinson, "Missouri Clinic Occupies Converted Firehouse," *Hospitals*, Vol. 41, December 1967, pp. 48-57.

⁹⁰ Richard M. Bailey, "Economies of Scale in Medical Practice," in Herbert Klarman (ed.), *Empirical Studies in Health Economics*, Johns Hopkins University Press, Baltimore, Maryland, 1970.

ent or, in the case of Deaf-Blind Centers and the State of Maryland, in a design and early implementation stage.

- Direction systems appear to yield high payoffs in those limited instances where even the most elementary information has been collected and used.
- The incremental cost of direction information is slight, compared with its marginal utility to the service recipient.
- A variety of direction service strategies exists in some crude form, but those responsible have not developed the strategies well or systematically; they are more "accidents" that grew out of some other purpose than they are deliberate creations in their own right.
- The critical elements in a direction strategy appear to be the following: mixture of services, definitions of the served population, catchment population size, catchment spatial features, staffing mix, follow-up, expedited flow of individual clients through the center, and independence from existing service agencies.

FOREIGN MODELS

Foreign models have many constructive lessons to offer about direction and other services. Two of this project's members, on two separate occasions in 1972, visited many European institutions and public agencies concerned with the handicapped. We benefitted greatly from this first-hand investigation, as well as from published reports on services for the handicapped in other countries, and relate some of those benefits in what follows.⁹¹

Rather than describing each program in exhaustive detail, the following discussion mentions only a select few interesting features that exemplify the direction concept and service, and indicates where an interested party might begin looking for further information on the issue.

An excellent, general summary of European activities has recently been completed by the Council of Europe. The section entitled, "Education of Parents and the Community," embodies many direction concepts.⁹²

Sweden

The Swedish tradition of excellence in the general area of health carries over especially to the care of handicapped children.⁹³ Besides attaining nearly total identification and registry of the population by virtue of the coverage guaranteed under the National Social Insurance Board, there are multiple institutional arrangements to insure that the handicapped child and his family are informed about

⁹¹ S. M. Genensky visited eight Western European countries in the course of a project on sensory aids sponsored by the Social and Rehabilitation Service of the Department of Health, Education and Welfare; he was particularly involved with closed circuit television for the partially sighted. G. D. Brewer remained primarily in Germany for a month as a guest of DATUM e.v. (Bonn-Bad Godesberg), where he was able to pursue inquiries about the German system and approach, and to obtain information about systems in other European countries.

⁹² Council of Europe, *Social Co-operation in Europe: Social Rehabilitation of Physically and Mentally Handicapped Persons*, Strasbourg, 1972, hereinafter cited as "COE."

⁹³ Obligatory Health Insurance has been in force since 1955, and extensive preventive pediatric care dates from the 1930s. Besides a general child allowance provided all parents, a special handicapped child allowance of approximately \$75 per month is provided on the supposition that being a parent of a handicapped child creates a chronic and additional financial burden, even over and above that accounted for directly by insurance payments for treatment and other defined services. This minimum allowance is adjustable upward, subject to a family-means test. Furthermore, the government either provides or covers the costs of transportation to receive services.

and receive needed services.⁹⁴ In this regard, the Central Registry has been pivotal in coordinating many of the more specialized services and in planning for the total needs of Sweden's handicapped population. It is reported that the Registry engages in monthly updates "in order to detect at as early a stage as possible increases in the incidence of certain types of malformation."⁹⁵ Around 90 percent of all children are given the equivalent of a multiphasic screening by the time they reach one year of age; such screenings are delivered in Child Welfare Centers located throughout the country. Follow-up and direction to all needed and available services are done mainly by nurses attached to the Child Centers. These Centers also conduct routine eye tests as early as age four, which results in a 3 percent rate of referral for services nationally; ear tests are also done, resulting in a 5 to 10 percent referral rate.⁹⁶

Care Boards, to plan, evaluate, and coordinate services to the mentally retarded of all ages, have consistently worked to "normalize" the life experiences of children by virtue of the Boards' physical location near ordinary schools and their encouragement of both families and educators to integrate the handicapped child into as many normal routines as possible.⁹⁷ This concept has been extended to preschoolers in Integrated Play Schools, whose function it is to mix impaired children such as the deaf or blind, with normal ones, encouraging the former to develop to a full potential and educating the latter to the simple fact that handicapped children are, after all, people too.⁹⁸

Denmark

From all indications, services to Danish handicapped people are also excellent relative to those in many other countries.⁹⁹ While driven generally by terms of the National Assistance Act, which "makes it the State's duty to care for all persons afflicted by any form of handicap and in need of special assistance,"¹⁰⁰ the Danish system is in transition. Prior to the execution of terms of the Public Health Security Act in April 1973, the system was a mixed, public-private one wherein the public component was concerned primarily with planning, evaluation, and coordination, and the private sector was largely responsible for service provision.¹⁰¹ Since April 1973, coordination and comprehensive service integration have been rationalized and placed under public control. Policies are set and interpreted at the national level; they are administered in 14 county-level jurisdictions (each having about 250,000 citizens), and in over 275 municipalities. Revenue is shared with the central government to pay for service provision. Direction occurs primarily at the municipal level, although a well-defined chain of authority and responsibility passes directly to the central government, aided by a general ombudsman system.¹⁰²

⁹⁴ Bo Hellstrom, "Society and the Handicapped Child in Sweden," *Journal of the American Medical Women's Association*, Vol. 24, March 1969, pp. 224-232; Eva Lindstedt, "Blind People in Sweden: A Socio-medical Study," *Acta Ophthalmologica*, Vol. 45, 1968, pp. 1146-1158; and Leopold Lippman, "Sweden Remembers—and Provides for—the Handicapped," *Mental Retardation*, August 1969.

⁹⁵ Hellstrom, *op. cit.*, p. 235.

⁹⁶ Lindstedt, *op. cit.*; Hellstrom, *op. cit.*

⁹⁷ COE, *op. cit.*, p. 19. Schools for the Blind, located in Stockholm and Orebro, have as residents only the most severely impaired; otherwise, they emphasize a parent-child instructional program that ranges in duration from two to nine months.

⁹⁸ Hellstrom, *op. cit.*, pp. 232-233.

⁹⁹ E. Johnson, "Modern Implementation of Denmark's Tradition of Health Care Delivery," *Health Services Reports*, Vol. 88, No. 7, August-September 1973, pp. 624-630.

¹⁰⁰ COE, *op. cit.*, p. 40.

¹⁰¹ *Ibid.*, p. 38.

¹⁰² Johnson, *op. cit.*, p. 630.

Early identification is stressed; so is early education, "preferably immediately after the diagnosis has been made, so that educational-psychological treatment can be started at the earliest possible stage."¹⁰³

A remarkable feature of the Danish approach is the use of Home Advisory Services (HAS), which offer to send a specially trained nurse for about three weeks into the homes of the handicapped to counsel, educate, and assess the progress of the child and the efficacy of services currently received. This service pursues nearly all of the purposes cited in our direction design objectives, plus an additional one—to help insure that the client *continuously* receives maximum benefit from the services he receives. Another interesting service of the HAS is the creation of individualized training programs for preschoolers that emphasize the parent's role; the program works as much with the parent (to relieve guilt, for example, and to train the parent to help the child) as it does directly with the child.

Belgium

Many notable direction concepts have also been institutionalized in Belgium, although the experiences there are less comprehensive than in Sweden or Denmark. The National Rehabilitation Fund, created in 1963, is a basic element of enabling legislation for handicapped programs; because of it, a number of specialized schools, training programs, public education efforts, and financing initiatives have been undertaken or supported. For instance, the Fund has made direct approaches to the National Federation of Industries and was instrumental in changing physician certification procedures to include required instruction in the full service needs of the handicapped.¹⁰⁴

Much direction, in the form of planning and service coordination, is evidently done through specialized schools for the deaf or blind. Schools also favor integrated research, testing, and screening practices;¹⁰⁵ they are in many aspects configured and operated along the lines of the Deaf-Blind Centers in the United States, a factor limiting the simple transfer of the institutional concept for many of the same reasons cited earlier for the U.S. case.

Two appointed bodies, having considerable parental participation, exist at the national level: the Central Council for the Handicapped concerns itself with the general implications (present and future) of policies affecting the handicapped, and the Central Family Council (dating only from 1967) tends to be oriented toward specific problems facing families of handicapped children. Both contribute in special and important ways to improved direction.

France

Much like that in Belgium, the French system allows voluntary (often officially sanctioned) bodies to take the lead in providing services to the handicapped. Public agencies provide some supervisory and financial assistance, and carry out rather specialized direction on behalf of categorical subsets of the handicapped population. For example, special inspectorates such as the Commission Départementale d'Orien-

¹⁰³ Kurt Kristensen, "Educational Care of Children with Extremely Low Vision," Paper read at the Conference of International Council of Educators of Blind Youth, Madrid, July 25-August 2, 1972. Kristensen characterizes the Home Advisory Service in his paper.

¹⁰⁴ COE, *op. cit.*, pp. 24, 46-47.

¹⁰⁵ O. Perrier, "A propos de l'enseignement de la réadaptation de l'enfant handicapé d'ouïe," *Acta Otorhinolaryngol Belgique*, Vol. 23, 1969, pp. 585-594.

tation des Infirmes insure that the quality, or at least the legality, of services provided to the young and to handicapped youth is maintained.

The complex "Social Aid Acts" basically underwrite a portion of the total costs of the handicapped and do so through complicated transfer arrangements with individual départements (roughly, "states"), municipalities, and quasi-public institutions. The Ministry of Labor, Employment, and Population is a major conduit of these funds at the national level.

An important, powerful voluntary organization is the National Federation of Associations of Parents of Handicapped Children (UNAPEI), which functions to educate the public in general, but concentrates on providing parents with information and direction. This is done through "family representatives" and a vigorous publications program.¹⁰⁶

Schools specialized to specific disorders exist,¹⁰⁷ and from all reports, carry out many direction-oriented activities on behalf of those enrolled.¹⁰⁸

Germany

Through a special "microcensus" taken in April 1966, it was estimated that somewhere between 450,000 and 500,000 school-aged, handicapped youth were located in the Federal Republic of Germany. A direction deficiency has hampered service delivery in Germany, where

... many organizations, institutions, and public authorities work on rehabilitation of the disabled. [The term "rehabilitation" has an all-encompassing meaning.] For the disabled, the distribution of competence [a very subtle word in German more connoting responsibility than it does wisdom or knowledge] is often confusing; coordination is hence required on both the individual plane ... and on the institutional and organizational plane, to guarantee continuous cooperation among all entities concerned about the setting up of necessary rehabilitation centers.¹⁰⁹

Discussion and analyses preceding a national decree of October 28, 1969,¹¹⁰ enabling the creation of rehabilitation institutions, focused on many of the same direction-related issues confronting the United States in 1974.

The "solution" to these issues is a many-faceted, and only recently widely implemented, collection of laws, directives, decrees, and appeals. It is worth noting the general character of the solution to get an inkling of what a strategy favoring a massive frontal assault on the direction problem could portend if adopted elsewhere. A desire to improve coordination, access, efficiency, and equity—in short, a concern for better direction—is the *only* common discernible thread knitting these activities together.

To extend and create rehabilitation centers, the Ministry of Labor and Social

¹⁰⁶ COE, op. cit., pp. 19, 20, 24, 38, 41, 48.

¹⁰⁷ One such is the Institut National des Jeunes Aveugles [National Institute of the Young Blind].

¹⁰⁸ Jean Crouzet, "Le rôle de l'ophtalmologiste vis-à-vis des enfants déficients visuels," *Bulletin des sociétés d'ophtalmologie*, Vol. 70, February 1970, pp. 212-221.

¹⁰⁹ "German Note on General Programs and Action Taken to Abet Coordination of Rehabilitation Work," Bonn: Ministry of Youth, Family, and Health; and Strasbourg: Council of Europe, PA/REHAB/71, June 7, 1971, pp. 1-2. We have assembled and reviewed a modestly representative German-language literature on these topics.

¹¹⁰ Basically a modification by decree of Section 62 of the Employment Promotion Act. The Act was a legal precedent calling for cooperation and coordination of employment and rehabilitation for all citizens that the decree seized upon and *generalized* to cover all services and *specialized* to focus on the handicapped.

Affairs allocated some 10 million DM in 1969 and 15 million DM in 1970. These funds are supplemented by large but undeterminable amounts from several federal ministries, most notably the Ministry for Youth, Family, and Health—the designated “cooperative and co-action” institution. The funds are being expended in five broad categories:¹¹¹

- Centers of medical rehabilitation (e.g., Wildbad, Heidelberg);
- Rehabilitation centers for specific disorders, e.g., heart (Bad Krozingen), brain (Bad Godesberg), eyes (Marburg);
- Vocational training centers;
- Sheltered workshops;
- Special facilities for children, e.g., day care, kindergartens, special schools;
- Homes for disabled persons.

In addition to expansion and construction of facilities, complementary training programs to staff the new buildings were instituted. Reconciliation and redrafting of conflicting federal legislation have begun (e.g., the Federal Social Assistance Act, the Youth Welfare Act, the Severely Disabled Persons Act, the national insurance codes, the Employment Promotion Act, and many lesser pieces of legislation all existed in some form but were not always mutually consistent, much less coordinated. “Harmonization” of conflicting federal and state laws and practices has been encouraged (German states have considerable power under the federal system, and this has proven to be particularly troublesome for easy achievement of the coordinative objectives). A consolidation of highly fragmented data into one information system has been recommended, along with the collection of needed new data. And multiple appeals for cooperation have been made to service providers at all levels of government, to industry and the trade unions, to the churches, to private agencies, to educational institutions, to the families of the handicapped, and to the population at large.

While it is too soon to make any overall assessments, these various activities have, if nothing else, raised the level of public awareness about the problems of the handicapped,¹¹² and have already produced a host of specific improvements.¹¹³

Given the many similarities between the German situation with respect to a direction service in 1968 or 1969 and the current situation in the United States, a careful monitoring and assessment of Germany’s implementation difficulties and realized (as opposed to expected) outcomes appears called for.

The Netherlands

Serving Dutch handicapped persons is the express responsibility of municipal authorities, although the central government has taken on many informational service activities. Programs for the mentally handicapped have been stressed, doubt-

¹¹¹ Interviews, Ministry of Youth, Family, and Health, Bonn, June 1972.

¹¹² As only one tangible example, a nationwide lottery whose proceeds benefit handicapped children is conducted with much anticipation, interest, and participation on a periodic basis. Results are announced on the “A Ray of Sunshine” television show.

¹¹³ A number of “Guides to Services for the . . .” and compilations of locally available services, resources, and institutions have begun to appear. Judging by the sheer number and variety of entries they commonly contain, they must be a considerable aid to families searching for help. One excellent handbook is the 175-page *Bundessozialhilfegesetz* (BSHG), issued by the Ministry of Youth, Family, and Health, Verlag Reckinger, Siegburg, June 1971. The handbook is categorized according to an extensive list of services, disorders, and pertinent laws, all discussed in simple terms. It is a “model” of sorts, easily replicated.

less because of their relatively greater numbers in a small total handicapped population, although direction and identification services are generally available to all.

Various institutional forms coordinate, plan, and deliver services. Foremost among these are 32 "Day Centers," each composed of a multidisciplinary team whose main task is to provide child- and family-oriented information, planning, guidance, and help; a strong, voluntary, national Parent's Association for the Mentally Handicapped, which has influenced legislation and serves as a "court of appeals" for parental grievances; and a Central Advisory Council on Care of the Mentally Handicapped. The Central Advisory Council has evidently concentrated its efforts on "normalization" activities—indirectly, with respect to changing public attitudes through a vigorous media program, and directly, by supporting the integration of the handicapped into ordinary schools to the maximum extent possible and by developing and disseminating correspondence courses for the families of severely handicapped children unable to participate fully in regular programs.¹¹⁴

Switzerland

Several features distinguish the Swiss delivery system, especially as it treats the informational services. The national Assurance Invalidité (AI) is financed 50 percent from private contributions of individuals, employers, and others, and 50 percent from the state. It maintains over 3000 local offices, each an accessible source of *referral* for a comprehensive range of services for some 2000 citizens. A Federation of Associations of Parents of the Mentally Handicapped¹¹⁵ works to educate the public and to reflect and advise on policy proposals (through an Advisory Council), and serves as a local spokesman in individual instances (mainly through an organization known as Pro Infirmis). The most visible of these efforts is an annual month-long public relations campaign.¹¹⁶

United Kingdom

Under national health or security legislation, such as the "Social Security and Supplementary Benefits Act," assistance is generally provided to the handicapped.¹¹⁷ However, a distinctive feature of the British system is a concern for independent assessment of the quality and equitability of services. That concern is best embodied in "Her Majesty's Inspectors"—objective, impartial, and usually personally respected people reporting directly to the appropriate Minister—in a number of program areas,¹¹⁸ and in professional certification demands contained in the National Health Service regulations.¹¹⁹ Additionally, two more specific direction activities have been observed: efforts by the Department of Employment and Productivity to coordinate job openings with individual capabilities by working directly with physicians,¹²⁰ and a general purpose, hospital-based information system de-

¹¹⁴ COE, op. cit., pp. 24, 48.

¹¹⁵ Much as in the Netherlands, the relative sizes of Switzerland's different handicapped populations tip the scales in favor of the mentally retarded. However, concern in fact is generalized.

¹¹⁶ COE, op. cit., pp. 23, 43, 45, 47, 49.

¹¹⁷ *Ibid.*, p. 38.

¹¹⁸ James Lumsden, "A Very Special Inspectorate," *Special Education*, Vol. 60, April 1971, pp. 18-22; and Department of Education and Science, *HMI: Today and Tomorrow*, Her Majesty's Stationery Office, London, 1970.

¹¹⁹ COE, op. cit., p. 27.

¹²⁰ *Ibid.*, p. 47.

signed to provide a full range of practical information to the handicapped and their families.¹²¹

A general preference for "normalization" is evident in extraordinary efforts to integrate handicapped children into ordinary schools to the greatest extent possible,¹²² efforts that appear to work reasonably well, for the deaf at least.¹²³

Observations on Foreign Models

It is hard to make detailed, general conclusions about the variegated array of European activities and systems, but certain features stand out, most of them related to the direction service:

- Direction services are better organized and developed in many European countries than in the United States.
- Regardless of governmental form or degree of service coverage supported publicly, nations with superior direction facilities and institutions tend to provide better and more extensive services.
- Each of various desirable features or characteristics of a direction service has been implemented, to a greater or lesser extent, in foreign applications, thereby supporting the feasibility of each feature in practice.
- Registration of the handicapped, often a routine by-product of a health insurance program (irrespective of the specific details of implementation of that program) can contribute significantly to early and periodic identification and to the periodic and systematic matching of the child's needs with a proper mix of services.
- More extensive and comprehensive services are provided in those settings where distinct lines of communication link parents with local, intermediate, and central governmental officials; i.e., "feedbacks" in the system are important.
- The provision of a full range of services through regional centers is feasible if the total (and hence total handicapped) population served by the center is absolutely small, or if the population served is made small by differentiating according to specific handicapping conditions. None of the countries we investigated combined both *full* service provision and *total* coverage of the entire handicapped population in a single national institutional setting.
- A potential option is to concentrate on a *single* service on behalf of the *total* population—an eventuality ruled out for any but the most generally demanded service, such as direction—and to provide this service through locally accessible institutions whose individual activities are coordinated by some superior authority.
- Because of severe contextual differences between the U.S. and foreign settings, none of the foreign models is entirely suitable for transfer en bloc to the United States, but many of them have desirable features that could be adopted in a United States direction service.

¹²¹ The design is explicitly oriented toward the client and not the administrator or service provider. Jean Cullinan, "Information Service for the Disabled," *Nursing Times*, Vol. 64, January 1958, p. 76. Created in 1964, the Information Service is the product of the joint efforts of the Disabled Living Activities Group of the Central Council for the Disabled, and the King Edward's Hospital Fund for London.

¹²² "No handicapped pupil should be sent to a special school who can be satisfactorily educated in an ordinary school." Ministry of Education Circular No. 276, June 1954.

¹²³ Ministry of Education, *Survey of Deaf Children Who Have Been Transferred from Special Schools or Units to Ordinary Schools*, Her Majesty's Stationery Office, London, 1963. The Survey found that except for the *most severely* impaired, about 1/3 were "successful," 1/3 "moderately successful," and 1/3 had been "failures" and returned to special units. See also Kathryn Meadows and Lloyd Meadows, "The Education of Deaf Children in England," *American Annals of the Deaf*, Vol. 113, September 1969, pp. 777-785.

RECOMMENDATIONS FOR REGIONAL DIRECTION CENTERS

We have identified and described a serious lack of direction services in the current system serving American handicapped children and youth. In the process, we specified several design characteristics for an improved direction service, and reviewed existing partial models that embody one or more of these characteristics and therefore could supply valuable inputs to a new and superior direction service for the United States.

We particularly commend certain aspects of the *conceptual approach* embodied in the New York State "Child Advocacy System," the *technical innovation* represented in Maryland's "Data System for the Handicapped," and a modified *institutional version* of California's Regional Direction Centers. Our proposed Regional Direction Centers for Hearing and Vision Handicapped Youth (RDCs) would be the result of judicious selection of the better features of these and other examples.

Specifically, we have three major recommendations, the first of which is:

Full-scale evaluations should be undertaken of the most promising existing partial models for providing direction service, to learn their strengths, weaknesses, and implications for an expanded, nationwide network of direction centers for hearing and vision handicapped children.

Our preliminary estimates of the eventual number, size, location, cost, composition, modus operandi, and institutional structure of these centers follows.

Number, Size, and Location. Based on the parameters generated in the California experience, there is a minimal national requirement for some 150 to 200 RDCs for Hearing and Vision Handicapped Youth. Since there are approximately 683,000 hearing and vision handicapped youth in the United States, this assumes a load factor of about 3500 to 4500 handicapped children per center, or equivalently, an average catchment area of some 1.0 to 1.3 million total population for each. Such a figure would tend to minimize travel times as much as possible, consistent with a large enough number of children served to enable the center to provide high-quality specialized services. These centers should be located at least one to every state and major standard metropolitan statistical area, with the remainder located to minimize travel times in more remote, less densely populated regions.

Cost. Our initial planning estimate is that each center could be operated for about \$100 per hearing and vision handicapped child per year. This would mean that if the child and his family received comprehensive direction service every four years on the average, then \$400 would be available to provide that direction. This amount appears adequate for at least minimum quality direction, and may even be a high estimate if volunteer help is used extensively, as in the New York Child Advocacy model.

One offsetting cost reduction would come from elimination of the need for other agencies to provide their present inefficient and partial direction based on little comprehensive information about the service system. In view of the potential for standardized, accurate, and rapidly accessible management information (currently nonexistent or available in only the most rudimentary forms), this \$100 expenditure would provide significant benefits. Additional humane, quality-of-life benefits to the children and parents from receipt of appropriate services are not calculable, but must be very significant. Benefits deriving from savings in services not needed by the youth later in life because of timely identification, evaluation of needs, and case management are also not calculable, but would be significant in the individual case and probably positive in the aggregate. The savings in rediagnosis and recertification realized by a simple transfer of client records from the center to various other

servers will be considerable, but not reliably calculable. The savings to be realized by a timely and accurate sensing of shifts in the number and character of the handicapped population—resulting from rubella or other epidemic problems, for example—could be significant but are not reliably calculable. The savings that would result from more efficient matching of the needs of a handicapped population with the locally available services are not measurable, using available data, but would be positive.

In brief, the cost per child for a direction service is not in itself excessively high, and the potential benefits and later savings from that service could be large, but cannot be accurately estimated.

Composition of Staff. The staff composition of individual centers will undoubtedly vary from site to site in response to local requirements and the availability of personnel. However, we think that a staff composed like the list in Table 3.4 would be a reasonable model and point of departure for individual sites. A representative table of organization is presented in Fig. 3.3; it shows the structural equivalence given to information collection and management; administration and case management; and service counseling and parent direction. The last-named is worth additional comment.

In addition to the direction provided by the center's permanent staff (by all staff members, not merely those we call Direction Counselors in Table 3.4), an unexploited and valuable source of counseling and direction is the parent of the handicapped child. Much of the day-by-day direction could be left to Parent Counselors who are members of the RDC's clientele and who would be available to help other, more recent initiates into the center's program and into the local service milieu. These Parent Counselors could be trained by and consult with the RDC's own permanent staff. Besides providing some much needed manpower, in an honest sense "ideally" suited to the parent information task, this innovation might do much to relieve the "What can the families do?" problem consistently noted in our family interviews and by professionals in the system; it is also a constructive step toward the participation objective.

Direction Counselors would be trained specifically for the RDC's purpose. They would not be social workers, psychologists, or counselors as conventionally defined.

Table 3.4

STAFF COMPOSITION MODEL FOR RDC

Director--a physician

Associate Director/Data Management--a data specialist
 Associate Director/Administrative Services--a skilled administrator
 Associate Director/Direction Services

Special educator
 Vocational rehabilitation specialist
 Social worker
 Public health specialist
 Psychologist
 Direction counselors
 Data management technician
 Parent counselors (volunteers)
 Consultant ophthalmologist
 Consultant optometrist
 Consultant otologist
 Consultant audiologist
 Consultant lawyer

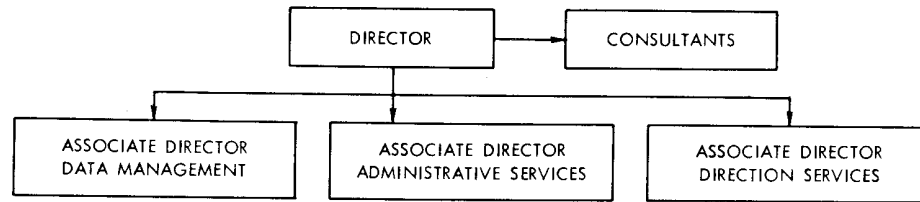


Fig. 3.3—RDC Table of Organization

They would constitute an important professional specialty that does not currently exist; their socialization, training, and orientation would be designed from the beginning to conform to the objective of serving the handicapped child and his family.

Parent Counselors and the professional staff of the RDC, with their knowledge of local information and conditions, could jointly develop correspondence courses and information booklets for use of the families served by the RDC. The courses developed and disseminated currently by the John Tracy Clinic in Los Angeles, which has pioneered in work with hearing handicapped youth, are a model of what is needed. Thousands of parents have benefited from these courses, but the courses' general potential has scarcely been tapped. Local information and conditions could be built into similar course material by the Parent Counselors and the RDC professional staff. Such courses can minimize costly face-to-face counseling time and enhance the benefits.

We recommend the early and more widespread use of correspondence courses, whether or not the more ambitious concept of the RDC is adopted.

Because some of the hearing and vision service specialists could not be effectively utilized full time, they could be hired on a consultant basis. A certain number of days' worth of consulting time would be allotted for use at the discretion of the RDC Director.

Modus Operandi. The major direct contacts that the child and his family will have with the RDC will be the initial intake and several other natural "milestones" related to the child's age and stage in the life process. For example, the "Case Management Flow Process," developed in California's regional centers, is a sound beginning and could serve as the intake or basic introduction to the RDC. That process includes the following steps: initial screening; intake; case staffing and plan formulation; plan execution; and periodic review and evaluation. We would amend this process somewhat to increase the "throughput," or rapidity of the RDC's service to clients. By defining *major* and *minor* periodic reviews and updates, annual costs per child could be held down. Major review periods would occur at initial discovery of the handicap; when the child reaches five years of age and is about to enter school; at nine years of age, when a detailed evaluation of school progress and prospects would be carried out; at fifteen years of age, when vocational services would become salient; and at twenty years of age, the "exit" age, to make a thorough assessment of the individual's needs and point out available services for adults, such as vocational retraining. Minor review periods would occur when the parent raised a specific question between the major reviews. In the event that the child's family moved from one region to another, this could signal the "Case Management Flow Process" to begin anew to match the child's needs with what is locally available.

Institutional Structure. The RDCs would be configured somewhat like the model outlined in Fig. 3.3. These centers would be placed in a chain of command

linking them directly to a State Advisory Council, which itself does not report to any existing agency providing other services such as health and education. To the greatest extent possible, this separate chain of command and compensation is needed to restructure incentives and to avoid "capture" by the existing service system. Finally, at the national level, we believe that a *strong* Office for the Handicapped within the Office of the Secretary of HEW would do much to focus attention on the needs of and serve as a spokesman for handicapped children and would serve admirably as a focus for coordinating existing services and all State Advisory Council and RDC activities. The Office for the Handicapped could have access to the information generated by the RDCs, and could be a vast improvement over the present multitude of uncoordinated groups that compete for resources at the federal level.

The following is our second major recommendation:

Based on an evaluation as noted above, a thorough implementation analysis should be conducted and five to ten pilot RDC projects should be created in locations throughout the country. Such pilot operations should themselves be carefully observed to insure that subsequent, full-scale implementation is carried out rapidly and with an absolute minimum of difficulty.

The need for direction is too important to permit implementation of the service to be sidetracked for reasons that could be avoided by sufficient foresight and planning. The pilot efforts would check out initial estimates of cost, modus operandi, staff composition, location, etc., and would serve as definitive factual examples upon which to base full-scale implementation.

Conducting pilot projects over a one-to-three-year period also "buys time" to accomplish several necessary jobs preliminary to full-scale implementation. It allows time for better design of the data system; it allows time for the legislative process to work through the many ramifications of the concept; it allows some time for the training of the specialized Direction Counselors; and it allows time for the idea's full impact to be absorbed by those who will benefit from and provide the services. The pilot project approach is one way to reduce risks without unduly inhibiting the adoption of the concept.

Our final recommendation:

Improvements in the Regional Direction Center design suggested by the pilot projects should be incorporated, and the concept should be expanded as rapidly as possible into a nationwide network of Regional Direction Centers for Hearing and Vision Handicapped Youth.

While we have noted the benefits such a proposal would afford to the families and children, it is important to stress that the present service system is also likely to benefit handsomely, because timely and efficient provision of services can eliminate duplication of effort and clients' need for other services later in life. We note again in closing this chapter that one of the aims of Regional Direction Centers is to complement and make the present system more efficient, and they would operate within the context of the present service system without major disruption of its present structure. However, if the information-based direction service is effectively provided, then localized conflicts may arise as the unevenness in the quality of existing service programs becomes apparent. When fully tested and developed for this relatively low-incidence population, the Regional Direction Center concept might be extended to include all handicapped youth and adults.

Chapter 4

IDENTIFICATION

INTRODUCTION

Broadly speaking, identification is the recognition and correct follow-up assessment of both a child's abilities and disabilities. While the bulk of the literature on the subject is concerned with recognition, follow-up assessment is at least as important in the service of the handicapped person.¹ Questions like the following illustrate the nature, importance, and utility of thorough identification:

- At what age is service intervention timely, and hence identification needed?
- How and by what institutional mechanism can the child's handicap be identified, and errors of identification minimized?
- What pathological condition underlies the disability?
- How seriously does the disability limit current and future functional capability?
- Are secondary disabilities likely to be "caused" by the basic condition, e.g., speech impairment because of hearing problems?
- Can the condition and disability be corrected, reduced, or prevented through timely intervention?
- How can a handicapped child be assured of proceeding beyond the stage of identification and into the stage of receiving needed services?
- Where can an appropriate range of services be obtained to minimize the handicapping effect of the disability?

It is easy to see that there is a clear and important relationship between direction—where diagnostic assessment is designed into the service from the start—and identification as a recognition process and activity.

While parents are usually the first to suspect hearing or vision impairment in those sensorially handicapped children that are identified, formal identification programs screen at least part of the child population in many states. Programs supported with funds from the U.S. Maternal and Child Health Service and Crippled Children's Service screened an estimated 10,000,000 children for vision impairment and 6,250,000 children for hearing impairment in 1973. Children in states with comprehensive screening programs usually are tested at more than one age, so the above figures do not represent children receiving their *first* screening.

Coverage of the population is far from universal. A 1969 survey of State Plans for the Maternal and Child Health Service and Crippled Children Service showed that: 12 states reported having some type of a general vision testing program, 20 reported some preschool vision testing, 19 reported school vision testing, and 2 reported glaucoma vision testing; 15 states reported some type of a general hearing test program, 11 reported some infants' hearing testing, 22 reported some preschool hearing testing, and 23 states reported school hearing test programs. Some additional screening is done under the state-operated but federally funded and regulated Medicaid program, which requires early and periodic screening, diagnosis, and treatment of Medicaid-eligible children.² It has been difficult, however, to elicit

¹ This distinction has been made well in Society of Medical Officers of Health, "The Needs of Handicapped Children," *Public Health* (London), Vol. 83, 1969, pp. 136-147.

² See Rand Report R-1220-HEW, pp. 176, 214.

compliance and full implementation of these provisions from the states. Data accounting for total numbers of people screened, referral rates, disease incidence, and follow-up measures undertaken are beginning to be collected, but the results are incomplete. To the basic question, "How many children were screened under this program?" asked by the U.S. Medical Services Administration in January 1973, 26 states either did not reply or did not have implemented programs.³ Thus, the present federal role with respect to identification programs is one of funding and research, but not operation or strong control.

Without proper and universal identification programs, no clear picture of the overall needs of the handicapped population can be drawn, and large known gaps in delivery of services to the handicapped population cannot be filled. Without adequately trained, certified, and funded screening personnel, misidentification (errors of both omission and commission) can be distressingly frequent. Lacking better informational connections between those specialists providing identification and other service providers, follow-up of individuals and their direction to an appropriate mix of needed services is often not done, or not done very well. Follow-up and adjustment of the total supply of services at the system level, to reflect changes in the number, kind, and distribution of the overall population are, for similar reasons, not done very well either.

Identification is one of the more neglected services. Even the best of the formal identification programs—the vision and hearing screening of children—are far from universal for school-age children, are often poorly implemented and are often nonexistent for preschoolers. This is unfortunate, for early identification is especially important in some cases, notably for deaf youth who need early language development assistance and for any youth with a treatable etiology causing degradation of sensory ability. Much of the identification that does occur is done informally by parents, schoolteachers, and others not specially trained to recognize handicaps.

As important as the identification service is, why is it so underdeveloped? Several explanations are possible. One plausible argument is that since all available service resources are being used already, it is pointless to go looking for more people. But that argument may be answered in at least three ways. An equity-related answer is that not all the people with the most need or the greatest ability to benefit are among those known to the service system. An adequacy-related answer is that if we were to identify more of those in need, the system might eventually respond with a more adequate level of resources. And an information-related answer is that even if the government chooses not to serve a handicapped person, he at least could be identified and armed with information about the exact mix of services he needs—information he will find helpful in seeking nongovernment-supported services.

In the remainder of this chapter we review problems with current identification programs, summarize the state of the art in identification techniques for children of various ages, and make several recommendations for improving the identification service. Our two primary recommendations are to:

- Implement mass screening programs to detect aural and visual handicaps in all young school-age children, with program mechanisms to insure quality screening techniques, personnel, and follow-up; and
- Since techniques for quality mass screening at birth for hearing and vision handicaps need further development, conduct thorough evaluations of various options for implementing identification programs for 2- to 3-year-old children, leading to the implementation of programs designed to reach 2-year-old chil-

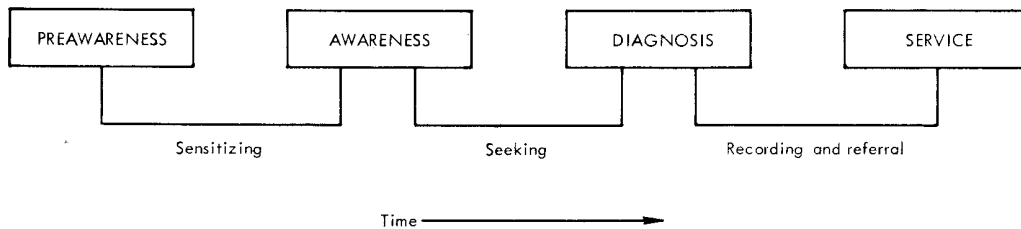
³ Ibid., pp. 199-201.

dren. Promising program options include a "high risk" registry established at birth, with follow-up examinations; and a type of "free check-up" mechanism whereby pediatricians or other service personnel would be reimbursed through National Health Insurance or some other program for each 2-year-old child they screen *and* report on to a health agency or other prescribed government agency.

PROCESS AND PROBLEMS OF IDENTIFICATION

The specific problems related to identification as a distinct service may be summarized in the following terms: (1) failure to detect handicapped children, (2) misidentification, (3) labelling and stigmatization, (4) inadequate follow-up procedures, (5) insufficient personnel training and certification, and (6) failure to create, use, and exploit technology. Each of these topics forms the basis for a subsection below.

We first characterize the "Identification Process" (see Fig. 4.1) to facilitate pinpointing several deficiencies in the current situation. This characterization was suggested by the Illinois Commission on Children, whose recent report we recommend as a creative and constructive approach to many of the problems noted in our report.⁴



SOURCE: Illinois Commission on Children.

Fig. 4.1—"Identification Process"

At the preawareness stage, the child is thought to be and is treated as "normal." No one has any inkling that the child is disabled. For a severely and obviously impaired child, this period may be as brief as the time between delivery and the first examination in the newborn nursery. For others, this stage may persist well into the school years, when learning or developmental problems should at last set the identification process into motion. The basic objectives of identification are to minimize the time lapse from preawareness to the delivery of needed services, and to minimize the chance that those services will *never* be delivered. Methods to attain those objectives form the bulk of the remaining discussion and underlie most screening and diagnosis procedures.

Sensitizing occurs when some person—a parent, neighbor, physician, relative, teacher—suspects that the child is "different" in some significant way. The process

⁴ Illinois Commission on Children, *Report of a Committee on Early Location and Care of Children with Handicapping Conditions*, State of Illinois, Springfield, Illinois, January 1972, pp. 13-14.

occasionally breaks down here because of what we might call "background noise" in communications between mothers (usually) and physicians. Physicians are all too familiar with the "anxious mother syndrome," wherein parents fall prey to the conviction that all sorts of things—usually illusory or exaggerated—are wrong with their children. The unfortunate result is that the physician, his alertness dulled from hearing so many false alarms, often fails to heed the mother whose fears are well founded.⁵ Sensitizing is the attempt to alert people in contact with children into being more careful observers, careful enough that the possibility of a handicap is not dismissed out of hand when a clue is presented that the child may not be "normal."

Awareness is the partially confirmed realization that the child's behavior or performance is abnormal for his age, plus perception of the ways and extent to which his performance differs. The awareness phase is where most mass screening programs are concentrated. All they generally seek to accomplish is to identify children who are not behaving or performing up to some normal levels expected for children of similar demographic and developmental characteristics. Awareness is *not* the same as complete diagnosis, although it is an important preliminary step to diagnosis.

Seeking is one form of follow-up. It is the critical step that sees the child through to more detailed and competent examination, usually by specialists in the *suspected* disorder. Since awareness is not diagnosis, the critical importance of competent and thorough confirmation and measurement of the disorder cannot be stressed enough.⁶ Failing a vision or hearing acuity test merely indicates that a child did not see or hear as normal children do in the test; it does not indicate why the child failed. For example, the child may have been distracted, may have had a cold, or may have been frightened by the test or the testing personnel. Nor does the test indicate what the child's unique residual capabilities may be, or whether intervention may improve or correct the condition. It takes competent, specialized assistance to begin making such determinations. Parents, as we have noted, are not always fully knowledgeable consumers; they probably require directional assistance during the seeking phase to get their children to the proper specialists for examination, and to help plan for obtaining the full set of services the child may need if diagnosis indicates a handicap.

Diagnosis is the *thorough* evaluation of the disability. Thoroughness in this sense comprises a full and forthright assessment of the disability, the services required and the most likely and desirable futures for the child. Besides the critical information an ophthalmologist or an otolaryngologist will bring to the diagnosis, the need for a full needs and service assessment should be stressed at this point.

Recording and referral, a frequently missing element in the identification process, pertains to the follow-up of the awareness and diagnosis. The most elegant and technically sophisticated diagnosis in the world is of little or no value if nothing is done as a result of it. If the child needs surgery, does he get it? Are the parents told what is needed and where to get it? If hearing aids or glasses are required, are the appropriate aids designated, are the parents told where to get them, are they taught

⁵ Some surprising statistics on identification are offered in G. Fellendorf and I. Harrow, "Parent Counseling, 1961-1968," *Volta Review*, Vol. 72, January 1970, pp. 51-57. The authors state that for children in the 0-6 age range, initial identification of hearing impairment is made by the parents in 70 percent of the cases, followed by grandparents and relatives at 16 percent, then physicians at 7 percent, friends at 6 percent, and teachers at 2 percent. The implications of this empirical finding are many, and include the need for rudimentary education of the newborn's parents to warn them of behavioral signs that may call for professional evaluation, and the need for physicians to take the parent's concern seriously.

⁶ The consistent reference made by parents in our family survey to this phase of the identification process must be noted here. It is addressed primarily in the chapter expressing our concern for developing and implementing better direction services, although its relationship to identification is also strong.

how to use and maintain them, and is the child trained in the use and importance of the aid?⁷

Service is the actual delivery of those services found to be needed in the diagnostic and referral stages. Did the child get medical and sensory aid service, and does the parent have some idea of what should be done in the home to help the child? Have schools and teachers been informed about the child's problem so they can arrange for seating adjustments in the classroom, placement in special education classes, and the like? Have follow-up visits been arranged, if needed, to check that the delivery service is accomplishing what it is supposed to?

Problems occur at each of these phases in the identification process. We consider only a few of the more general ones in the following discussion.

Failure to Detect Handicapped Children

There is no formal institutional mechanism to screen and identify aurally or visually handicapped children after they leave the newborn nursery until they enter elementary school, usually at age five. Screening of school-age children occurs in many locales, but is far from comprehensive.

In our companion report, R-1220-HEW, and in later sections of this report, we document the large fractions of the population of handicapped youth that are not receiving needed services. The question then becomes: do the service programs typically know who the unserved youth are? That is, have these youth usually been identified but not been served? The answer is clearly no. In our interviews with personnel in over 30 different state agencies in Arkansas, California, Illinois, Massachusetts, and Wyoming, we routinely asked if the service agency knew who the unserved youth were. Aside from an occasional official who mentioned a short waiting list, the response to our question was that no, the agency did not know who the unserved were by name. Usually, these officials could do no better than to say they assumed the unserved children were more predominant in rural or innercity areas. The lack of identification is not surprising since comprehensive identification programs do not generally exist.

Failure to identify handicapped children may be related to a general inadequacy of resources to treat and care for more children than are already being served. If there were better and more complete identification of disabled children, there would be some undeniable obligation to do something for those who are discovered. The prospects of a thorough identification program, particularly with respect to the "missed cohort" aged 0 to 5 years,⁸ present several logical, strategic options for service provision, as summarized in Fig. 4.2.

Under option "a," existing levels of identification effort would be reduced or, at the limit, eliminated altogether. At the same time, the reduction in service demand that this would probably generate would be translated into a reduced total bill for all types of services. For the national context, this would represent a "get out of the business" strategy; for less inclusive contexts, such as a local area or even a state, it would be a strategy of "transfer the problem elsewhere."

Reducing identification efforts while maintaining the current level of service

⁷ Once again, our family surveys have very little that is positive to say about this aspect of the current identification programs.

⁸ Even in relatively affluent and sophisticated local settings and programs, the number of children who *do not see a physician* in the 0 to 5 years of age period may be as high as 25 to 30 percent of the total population in the cohort (interview, Dr. Frederick A. Frye, Department of Pediatrics, Children's Hospital, San Diego, California, February 1972). This in itself is a point worthy of additional empirical investigation.

Identification Resources	Treatment and Follow-up Resources		
	Decreased	Maintained	Increased
Decreased	a	b	c
Maintained	d	e	f
Increased	g	h	i

Fig. 4.2—Possible strategic options: levels of identification versus levels of treatment and follow-up

expenditures, option "b," could have several outcomes: it might mean that service levels to those already in the system or fortunate enough to get in "naturally" would be maintained or improved, or it could mean that services would be concentrated on those who are more severely impaired. Such a strategy is plausible in the case of hyperinflation of medical costs for example.

If one decreased identification resources while increasing other system resources, option "c," services might improve for those fortunate enough to receive them, or the variety of services might be expanded. This strategy fosters the illusion that "excellent" services are provided, but the illusion is created at the expense of some number of the population in need.

Maintenance of the status quo in identification also could have three accompanying levels of other service expenditures; that is, other service provision may decrease, remain the same, or increase. When the total capacity of the service system is reduced (option "d"), we arrive at a fair representation of some of the current government service programs, faced as they are with rapidly expanding and inflating medical and other service costs (which result in a net real loss in total buying power). The status quo is represented in option "e." The system's other-service capacity may be increased while the present level of identification is maintained (option "f"); the line of thought behind this option can be roughly expressed as, "We have more than we can take care of adequately now, so let's just serve those we know about better."

Options "g" and "h" call for increased identification efforts, but with either reduced or steady levels of total service provision—two variants of the attitude, "Let society take care of the children, but find as many of them as possible."

Finally, there is the possibility that both identification and total service provision will increase, as indicated in option "i." This option would realize many of the stated objectives of those responsible for the service system,⁹ and it is certainly the

⁹ R-1220-HEW, Chapter 4, "The Issue of Goals and System Performance."

option that would generally satisfy the handicapped and their families to the greatest extent.

This exercise summarizes a number of extremely difficult choices confronting this or any other society when faced with the problems of lack of identification and services. The choices bristle with thorny moral, economic, and ultimately political considerations. On the one hand, it is in the clearest interest of the disabled child to be made aware of his problem and to be diagnosed (and the earlier the better, if remedial services are to have greatest possible efficacy). On the other hand, at a total societal level, more and better identification may impose costs. The tacit recognition of some of these costs may underlie many poor identification programs or explain the absence of any programs at all. Which course is the more prudent for our society: minimal identification and "acceptable" services to those identified—approximately the current national situation; or maximal identification and either inadequate or more costly services? In approximate terms we have shown that something like one-half of the handicapped youth between the ages of 0 and 21, in need of any specific type of service, are not receiving them.¹⁰ With total identification, the current annual governmental expenditure for services to handicapped youth of some \$4.7 billion would be more like \$9 to \$10 billion. With total identification and the present quality of service delivered to all hearing and vision handicapped youth, current government expenditures would rise from the present \$420 million to perhaps twice that much. Is society willing to face this prospect squarely, a willingness at least partially implied in an honest commitment to find as many handicapped children as possible?¹¹

When one turns from the contemplation of society's goals, he bumps headlong into a host of more prosaic reasons that many handicapped children are not identified. While we consider several of these as they pertain specifically to the aurally and visually handicapped, we suspect the reasons are more general.

The unavailability of reliable, timely, and comprehensive information about the overall handicapped population means that we do not really know very well what to be looking for and when to look for it. Furthermore, there are other reasons that many children are overlooked: (1) Lower socioeconomic groups consistently do not share in society's goods and services, and identification services are no different from others in this respect. (2) Many "high risk" children—those born prematurely, or to mothers who have had little or no prenatal care, or born under great stress, or to parents with abnormal clinical or genetic histories, and so on—are not registered and given the benefit of extra and more thorough examinations, even though extra attention is indicated based on the statistical likelihood of disability associated with "high risk birth". (3) Services are not equitably divided between populous and more remote regions or between rich and poor districts of a given locality. And (4) some handicapped children are simply denied services and kept from society's full view by ignorant or guilt-ridden parents—most notably, the "closet kids" reported in the newspapers from time to time. All of these factors diminish the prospects of complete identification; but several may be addressed and their effects lessened, presuming one honestly wants to provide identification and other services on as equitable a basis as possible to all of those who could benefit from it.

Later in this report we shall concentrate on the serious problems of the "missing cohort" aged 0 to 5, although we are well aware that other factors are operating to

¹⁰ Ibid.

¹¹ Full commitment would be indicated if total resources were likewise increased in the face of the increased demand generated by better and thorough identification.

inhibit complete identification of those in need. This concern has been well summarized in a recent statement of the American Academy of Pediatrics.

At present there is a serious obstacle to identification of health problems in the preschool child; only a small section of the child population receives continuous health care and supervision from infancy to school age. Early identification of handicapping among those children who receive health care from either the private or public sectors of the delivery of health care can be furthered by emphasizing the need for comprehensive screening procedures. But early identification of physical handicaps among those children who do not receive health supervision during infancy and childhood poses almost unsolvable problems. In our society children are not brought together regularly in groups until school age, and therefore it is currently almost impossible to conduct screening examinations on this population at an early age.¹²

The principle of early and correct identification, so prominent in the above statement, is a common one;¹³ however, while not doubting its legitimacy, we shall discuss difficulties in implementing it in the next section of this report. In particular, the ideally timed early identification program—a high-quality neonatal vision or hearing mass screening program¹⁴—does not appear technically feasible at present. In short, the problem of early preschool identification will not be resolved by any “easy” recommendation or “quick fix.” Like the general system in which it is embedded, it is too complex for that.

Misidentification

Identification presents, in one sense, the classic statistical problem of error types. In this setting, Type I errors occur when children who are not handicapped are screened and erroneously labelled handicapped; Type II errors occur when screening fails to detect children who are in fact aurally or visually handicapped. If the handicapped child is not identified, he may either be labelled “normal” or, what is potentially worse, he may be erroneously thought to have some nonsensory handicap such as mental retardation.

Excessive Type I, or “false positive,” errors would indicate that screening procedures are too conservative or perhaps unreliable. Too many “false positives,” if referred for specialized diagnostic procedures, may overload scarce and expensive diagnostic resources and gradually erode diagnosticians’ trust in the seriousness or worthiness of the screen program. Nor should the injurious effects of misidentifica-

¹² American Academy of Pediatrics, *Lengthening Shadows: A Report of the Council on Pediatric Practice on the Delivery of Health Care, 1970*, The Academy, Evanston, Illinois, 1971, pp. 56-57.

¹³ The general case is spelled out in K. Eileen Allen et al., “Early Warning: Observation as a Tool for Recognizing Potential Handicaps in Young Children,” *Educational Horizons*, Winter 1971-72, pp. 43-55, where Head Start, day care, and preschool nursery contacts with children are thought to be an underexploited and possibly important source of identification referrals. The case of early visual detection is made, for example, in R. W. Dockery, “The Value of Vision Screening in the Preschool Age Child,” *Journal of the National Medical Association*, Vol. 52, 1960; and J. W. Oberman, “Vision Needs of American Children,” *The Sight-Saving Review*, Vol. 36, Winter 1966, pp. 217-227. Similar arguments are common in the hearing literature, as illustrated in A. Glorig, “Routine Neonate Hearing Screening: Summary and Evaluation,” *Hearing and Speech News*, Vol. 39, No. 1, January-February 1971, pp. 4-7; and in C. P. Goetzinger et al., “Small Perceptive Hearing Loss: Its Effect on School Age Children,” *Volta Review*, Vol. 66, 1964, pp. 124-132.

¹⁴ “[Because] results of mass screening programs are inconsistent and misleading. . . we urge increased research efforts, but cannot recommend routine screening of newborn infants for hearing impairment.” Committee on Fetus and Newborn, “Joint Statement on Neonatal Screening for Hearing Impairment,” *Pediatrics*, Vol. 47, No. 6, June 1971, p. 1085.

tion on child and parent be ignored. It is shocking to be told that you are the parent of a "defective" child; but it is also tragic to labor under this impression only to find that it is untrue. Some Type I errors are to be expected, however, when test subjects are very young and hence uncooperative, when the test instrument or device is known to have a significant margin of error, or when the testing personnel are inexperienced and make judgmental and procedural mistakes. Should any or all of these conditions hold in the actual test situation, several alternatives should be considered to reduce the impact of Type I error, since one "cries wolf" only so often until the cry is ignored.

- Personnel may be trained better, certified, supervised, and exposed to more screenings to gain experience.
- The test instrument may be evaluated and improved.
- One may work with a more "cooperative," i.e., an older or less impaired, population.
- Or, a second and third retesting may be performed on all positives initially screened to confirm the first identification and to minimize false positives before they are referred to a diagnostician.

Excessive Type II errors, in which handicapped children pass undetected, would indicate that the identification procedures are not discriminating enough. Too many "false negatives" could damage children by denying them needed services. Type II errors of identification should be expected when the handicap is slight, latent, or overshadowed by other more obvious problems, when the test instrument is faulty or too "coarse grained" to discriminate the condition, when testing personnel are not properly trained and supervised, or when the aural or visual handicap can be confused with some other handicap, as when a deaf child is incorrectly thought to be mentally retarded. One should think about the following remedial actions if excessive Type II errors are encountered in a given identification program:

- Train the personnel better, certify them, and alert them to the often subtle, subjective cues that may signal the presence of a handicap.
- Improve the test instrument, especially to increase the level of resolution to pick up more children with both severe and mild handicaps.
- Or, repeated tests could be given, both immediately and over time, with the same or similar, complementary instruments to give the disability every opportunity to demonstrate its presence. Such a procedure is particularly suitable for progressive or degenerative disabilities, e.g., the Wardenburg syndrome as an etiology of deafness, and for "high risk" populations.

The special problems attendant to screening multiply handicapped and other hard-to-test children deserve special mention as a persistent source of misidentification, particularly in a total handicapped population that appears to include increasing percentages of congenitally and multiply handicapped children.¹⁵ In the case of the mentally retarded child, for instance, there is no reason to believe that a "normal" screening test will reliably indicate either sensory competence or deficiency. Perhaps the mere presence of some other defect, such as mental retardation or a learning disability, should entitle the child to a full aural-visual diagnostic evaluation. Statistically, there is reason to believe that children with other types of handicaps have a greater than average probability of being aurally and visually impaired

¹⁵ This observation is occurring more in the literature. For example, see J. T. Fenlason, "An Occupational Therapy Program for the Developmental Habilitation of Congenital Rubella Children," *American Journal of Occupational Therapy*, Vol. 22, November-December 1968, pp. 525-529.

as well, and administrative-legal procedures may be needed to insure they receive hearing and vision tests. There is also some demand to improve diagnostic procedures themselves, but that is a far more difficult matter, best left to medical specialists for resolution.¹⁶

Labeling and Stigmatization

In the zealous endeavor to find the handicapped child, one often loses sight of the personal, familial, social, and legal consequences of the "simple" act of identification. To cite the most extreme case in recent history, it was a mere thirty years ago that Nazi Germany systematically exterminated thousands of humans "simply" labeled mentally defective. While far less lurid nowadays, the negative consequences of labeling still persist.¹⁷

In a thorough recitation of the issues and legal precedents related to classification of handicapped children in and by schools, David L. Kirp has provided many of the legal underpinnings for a "Children's Bill of Rights."¹⁸ His discussion bears careful and thoughtful reading; we summarize here a few of the more salient issues he raised concerning the problem of labeling and stigmatization.

A basic principle guaranteed by the law is that a child's liberty may not be infringed upon unless adequate procedural protections are provided.¹⁹ Specifically, courts have endorsed the concept that labelling a child mentally retarded or delinquent may not be used as a tactic to relinquish the obligation to educate the child, one area where this society has established a minimum demand and expectation for service.²⁰ One could likewise argue a related and more general case, although the argument has not yet met the legal test, that failure to classify a demonstrably needy and disabled child for the purpose of denying an expensive or scarce service would appear to be a denial of dubious legality.

The basic issues involved in the identification/classification act revolve about questions of the accuracy of the classification²¹ and of the appropriateness of the

¹⁶ The literature is not large, but some concern is evident. M. D. Sheridan, "Vision Screening of Very Young or Handicapped Children," *British Medical Journal*, Vol. 2, 1960, pp. 453-462; Robert T. Blackhurst and Edmund Radke, "Vision Screening Procedures Used with Mentally Retarded Children—A Second Report," *The Sight-Saving Review*, Vol. 38, No. 2, Summer 1968, pp. 84-88; W. S. Schachat et al., "Ophthalmologic Findings in Children with Cerebral Palsy," *Pediatrics*, Vol. 19, April 1957, pp. 623-628; J. D. Schein and J. A. Salvia, "Color Blindness in Mentally Retarded Children," *Exceptional Children*, Vol. 35, April 1969, pp. 609-613; R. G. Suchman, "Visual Impairment Among Deaf Children," *American Journal of Ophthalmology*, Vol. 77, January 1967, pp. 18-21; R. T. Fulton and L. L. Lloyd, *Audiometry for the Retarded*, Williams and Wilkins, Baltimore, 1969; and L. L. Lloyd et al., "An Operant Audiometric Procedure for Difficult-to-Test Patients," *Journal of Speech and Hearing Disorders*, Vol. 33, No. 3, August 1968, pp. 236-245.

¹⁷ See John T. Chandler and John Plakos, *Spanish-Speaking Pupils Classified as Educable Mentally Retarded*, State Department of Education, Sacramento, California, 1969, which responded to the fact that in 1969 some school districts had as many as 85 percent "educable mentally retarded" with Spanish surnames. The problem was linguistic, not intellectual; the result was legislation to require intelligence testing in one's mother tongue and the consequent "delabeling" of several thousand EMR children throughout California.

¹⁸ David L. Kirp, "Schools as Sorters: The Constitutional and Policy Implications of Student Classification," *University of Pennsylvania Law Review*, Vol. 121, No. 4, April 1973, pp. 705-797. (Republished under the same title as Reprint Number 1, Childhood and Government Project, The Earl Warren Legal Institute, Boalt Hall, University of California, Berkeley, 1973).

¹⁹ *Wasson v. Trowbridge*, 382 F.2d 807 (2d Cir. 1967); *Goldwyn v. Allen*, 54 Misc. 2d 94, 281 N.Y.S.2d 899 (1967). See generally, Van Alstyne, "The Judicial Trend Toward Student Academic Freedom," *University of Florida Law Review*, Vol. 30, 1968. (Citations are from Kirp, op. cit.)

²⁰ Buss, "Procedural Due Process for School Discipline: Probing the Constitutional Outline," *University of Pennsylvania Law Review*, Vol. 119, 1971, pp. 611-612.

²¹ *Kent v. United States*, 383 U.S. 541 (1966); and *Holmes v. New York City Housing Authority*, 398 F.2d 262 (2d Cir. 1968) (authority must articulate standards for admission to public housing.)

proposed treatment.²² The procedural guarantees afforded by the law to handicapped persons in presently limited circumstances pertain specifically to a full and comprehensible explanation of the proposed actions, and a hearing prior to taking certain actions.²³

Before reclassification . . . the school [constituted authority] should inform the family and the child affected, to explain the proposed action and to indicate what alternatives might be available. If such a process actually functioned—if parents and students understood “what the government is doing to [them]”²⁴ and voluntarily approved that determination—the need to secure the more formal protections of due process might well disappear.

.....
Once he is removed from the mainstream of the school, injury has been incurred. It is a clear message of *Constantineau* that a hearing should be provided before the imposition of a stigma. Similarly, during the period that he is misclassified, the child suffers educational deprivation.

The problem of misclassification and/or misreferral of persons who are not in need of service is also considered in the law.²⁵

One possible outcome of an increased consciousness of the costs involved in labeling may be a more judicious use of the classification mechanism. Another outcome might be the extension of this considerable body of legal precedent from the substantive area of education to protect the rights of handicapped children more generally. Even if not more judicious, the labeling and classification processes are bound to become more public as wrongfully labeled people seek redress from the courts for real and imagined grievances.

The creation of functional classifications, another possible outcome of the legal machinery, has been advocated in the past.²⁶ It may develop as a way to scale a disabled person’s total residual capabilities, and thereby replace mechanistic, simplistic, either/or labels such as “legally blind.” Such functional classifications are implicit in our earlier argument calling for a *thorough* diagnosis and evaluation of the disability and the required services. For several reasons, therefore, efforts to create and execute such functional classification schemes appear to have considerable merit.

Current vision and hearing testing procedures attempt to determine the levels at which the subject fails an acuity test. For example, at what distance and size of figure on an eye chart, or at what level of dB of hearing loss, is he unable to perform? Such tests prove only that the subject cannot see or hear at the prescribed distance or with the noted level and tone of sound; they do not establish his total sensory capability. In contrast, one wonders what might happen if the test objective were to determine the person’s aural and visual functional capability in reading, writing,

²² *Pennsylvania Association for Retarded Children v. Pennsylvania*, 334 F. Supp. 1257, 1260 (E.D. Pa. 1971).

²³ Kirp, *op. cit.*, pp. 787-788.

²⁴ The reference is to *Wisconsin v. Constantineau*, 400 U.S. 433, 437 (1971).

²⁵ In reviewing welfare payment cutoffs, the Supreme Court has insisted that a due process hearing be provided prior to the cutoff. *Goldberg v. Kelly*, 397 U.S. 254 (1970). The harm done by “educational cutoff” may be regarded by courts as even more substantial. Cf. *Palmer v. Thompson*, 403 U.S. 217, 229 (1971).

²⁶ S. M. Genensky, *A Functional Classification System of the Visually Impaired to Replace the Legal Definition of Blindness*, The Rand Corporation, RM 6246-RC, April 1970; and Jack Sokolow and Eugene J. Taylor, “Report of a National Field Trial of a Method for Functional Disability Evaluation,” *Journal of Chronic Disability*, Vol. 20, 1967, pp. 897-909.

mobility, and speaking or understanding speech. This is a very different conception of identification than presently exists, a conception whose objective is to evaluate the subject's residual capacity to function, and not to limit him by applying gross labels such as "blind," "deaf," or "deaf-blind."

The point here is the need to emphasize a person's best and total capability to function in a situation, as opposed to the present "worst case" emphasis that appears to underlie many labels. For people labelled "deaf-blind," this might mean the useful recognition that most have some residual capability in the aural and/or visual senses; very few are both profoundly deaf and totally blind. In fact, there is great diversity in the overall population labeled "deaf-blind;" diversity that must be recognized, especially by legislators and high level administrators, if proper service and a better service system are to be provided.

Inadequate Follow-Up

There is a major problem in getting children who fail vision and hearing screening tests to a place where they can receive competent, professional diagnostic services. That is to say, there are two breakdowns in the "Identification Process": between both the "Awareness" and "Diagnosis" and the "Diagnosis" and "Service" phases.

Breakdown in the first instance occurs when a child has been screened and is thought to be impaired, but nothing is done to get him to a competent source of medical-diagnostic service. Breakdown in the second instance is thought to be less frequent, but is still notable; it occurs when the child has had a full diagnostic work-up but nothing is done to provide the services indicated by the nature and the extent of the disability and recommended by the diagnostician.

A screening program is nearly worthless without follow-up. The problem itself might be attacked simultaneously from several angles. General publicity about the nature and importance of detection of preschool vision and hearing problems might help, for instance.²⁷ Parents who are so informed, either through the media, by school personnel, or by their physicians, might give the general problems more attention, being alert to recognize gross signals of disorders in the child and to search out competent care. The critical importance of the pediatrician and the general or family practitioner has not received the attention warranted. In their penetrating critique of neonatal hearing evaluation, Goldsen and Tait made several pertinent observations on this point.

- Pediatricians are in the most contact with the child in the 0-5 period, if the child is seen by a physician at all.
- Pediatricians are generally not sensitized to a full range of signs and symptoms indicative of sensory disorders.
- More should and could be done to improve on this situation by repeated exposure of the need for identification to the pediatrician in professional meetings, journals, in-service training, and other educational activities.

²⁷ The National Society for the Prevention of Blindness is to be commended for their program of dispensing free "Home Eye-Test Kits" for preschoolers. It is a simple test using a version of the illiterate "E" which can be used by the parent to spot fairly gross problems in about five minutes. Kits are obtainable from the Society by writing them at 79 Madison Avenue, New York, New York 10016. There is even a response card which the parent is asked to fill out and return to the Society so that they can evaluate the effectiveness of the program. On this return card, the parent may indicate that they did not use the test, that the child used and passed the test, or that the child was unable to pass a minimum standard and that an appointment for an eye examination had been made with a physician or optometrist (whose name and address are requested).

- Pediatricians do not normally have occasion to know and use audiologists [and other specialists in sensory problems], but this shortcoming could be reduced through individual initiative and through direct action by local medical societies.
- There is great and pressing need for more and better staffed well-baby clinics to increase the institutional chances that children in the "missing cohort" aged 0-5 will see a physician.
- The use of mobile hearing testing units, taken as part of a strong, general medical evaluation service, is an underutilized and underappreciated mechanism to realize contact with the 0-5 age group.²⁸

Another and more difficult aspect of the breakdown phenomenon deserves more investigation: Why do parents either seek or not seek medical and other care for their children in the first place? What incentives operate in this matter? When we have complete answers to these "simple" questions, we will begin to know how to provide not only better screening follow-up but better services generally to our children.

Parental cooperation underlies an effective service program. Most parents respond well, but there is some proportion who, for whatever reason, will not take their children to the optometrist or audiologist for more detailed examination or to the ophthalmologist or otologist for a thorough medical workup, if that is called for. Delay can be a serious enemy for the impaired child. If there is difficulty in getting parents to obtain hearing aids for their children, for example, or if there is some problem with the parent's acceptance of special service regulations, then the parents need to be educated or the regulations modified. The school or public health nurse may be helpful in this regard. The recommended Regional Direction Center may have a pivotal responsibility in this task to insure that the diagnostic examinations recommended by the screening program are made and made on time, and to check that services are having the effects they are supposed to have.

Follow-up is too important to be left to chance, and responsibility for it must be carefully and clearly defined early and throughout the handicapped child's life. It is time-consuming, frustrating, and demanding work, but doing it correctly has been demonstrated to have considerable positive benefits.²⁹

Insufficient Personnel Training and Certification

The need for well-trained and certified personnel has been noted occasionally in the literature as one explanation for uneven and unreliable screening programs.³⁰ The value of qualified vision screening technicians has been demonstrated over the years in the Michigan program.³¹ The need for certification of those actually doing

²⁸ Robert Goldsen and Charles Tait, "Critique of Neonatal Hearing Evaluation," *Journal of Speech and Hearing Disorders*, Vol. 36, No. 1, 1971, pp. 3-18.

²⁹ The State of Michigan's vision screening program has been hailed in the literature as being exemplary. One of its key features is the well-developed follow-up procedure that forms an integral feature of the overall program. Parents are notified if their child fails the initial screening; a doctor's report form is included, which the parents are asked to have completed and returned to the Department of Public Health; if in six weeks no report is returned, a follow-up letter reminder is mailed out; and if that does not work, public health and school personnel are quite likely to pay a visit on the family to encourage them to make an appointment. It works. See Robert T. Blackhurst and Edmund Radke, "School Vision Screening in the State of Michigan," *The Sight-Saving Review*, Vol. 34, No. 1, 1964.

³⁰ J. W. Black, "Procedures for Children," *ASHA Reports No. 2*, 1967, pp. 27-38; and J. P. Moncur, "Judge Reliability in Infant Testing," *Journal of Speech and Hearing Research*, Vol. 11, 1968, pp. 348-357.

³¹ Blackhurst and Radke, op. cit.

preschool aural and visual screening has been repeatedly noted in our interviews with speech, hearing and vision specialists.

Comprehensive state screening programs are so few that there is a reduced demand for these very particular technical skills. Black and his associates stress this point, noting without sufficient jobs there is little reason to train technical specialists, but without technical specialists, there is little reason to expect screenings to improve in either quality or quantity.

Failure to Exploit Technology

Adequate screening technology exists for school-age children; the problem is to screen very young preschool children. There are many embryonic technological developments in preschool identification, a point stressed in our review of "the state of the art" in the next section; however, the researcher soon forms the distinct impression that, lacking a central or at least recognizable focus for identification as a service,³² much apparently promising embryonic technology is not being developed to see if it can become practical and be exploited.

For instance, promising but undeveloped technology for screening of neonates for hearing deficits has been reported in the open literature since at least the mid-1960s. There is little comparable literature or experience evaluating these promising techniques in depth, developing and determining their feasibility in an applications setting, or exploring their likely costs and benefits for limited, selected, or mass use. There are many promising technological tools around which, if evaluated, compared, and refined for large-scale applications, could undoubtedly help to strengthen the identification service.

In short, a remarkable variety of technology for preschool age screening exists in experimental form. The connection between research and applications, a connection associated with careful evaluation, studies of feasibility, and assessments of desirability, is not very well made in the current system.

SCREENING TECHNIQUES AND PROCEDURES FOR AURALLY AND VISUALLY IMPAIRED YOUTH

One important by-product of a good sensory-impairment identification program would be information about the nature, extent, and characteristics of the impaired population.³³ That information is central in bolstering policy arguments, and age-specific differences in the data should be reflected in policies. Because they lack badly needed data, many decisionmakers have to rely heavily on subjective judgment as they go about setting priorities and allocating resources. Age-specific information would enable empirical calculations of such factors as lost years of life or personal independence, future income sacrificed, and so on. The death of a male infant, from this perspective, represents 67 years of life, about 40 prime reproductive years, and about 50 years of economic productivity. Death by accident for 20 to 49 year old

³² The National Institute for Neurological Diseases and Stroke, and the National Eye Institute, have a long and commendable record of sensorineural research (See Rand Report R-1220-HEW, Chapter 9). There is a difference between much, if not most, of this kind of research and the more prosaic requirements of developing and evaluating identification techniques for mass screening programs.

³³ Barkev S. Sanders, "Measuring Community Health Levels," *American Journal of Public Health*, July 1964, pp. 1063-1070, indicates some of the effects in health care delivery resulting from better or more complete mortality and morbidity data.

males is more "costly" to society in terms of lost years of life and total productivity than all deaths from the three leading causes for all ages, stroke, cancer, and heart disease, and yet relatively less attention is devoted to accidents.³⁴ One partial explanation for this emphasis is clearly related to the lack of data and subsequent popularization of data in age-specific terms.

The costs and feasibility of identification programs of course must be considered. In broad terms, we recommend a "mixed scanning" approach to identification, by which we mean giving all children a minimum but sufficient opportunity to demonstrate impairments and, if once demonstrated, a maximum opportunity for thorough and accurate diagnosis.³⁵ It is infeasible, unnecessary, and too costly to gather finely detailed information on all youth of all ages. However, it appears necessary to improve on the present situation, in which an at-birth medical examination (with little or no attention to testing sensory ability) is often followed by almost a total blank until the child receives a school-entrance medical examination at age 5, and in which a large fraction of school-age youth are not screened for sensory impairment. It would be desirable for both preschool and school-age children to have a greater opportunity to receive a more detailed hearing and vision examination, and, if found to be handicapped, to receive the best possible diagnostic confirmation of sensory impairment. If "awareness" is fostered by low-cost screening procedures, the higher costs of carrying out detailed diagnostics are more readily justified.

Importance of Vision Screening

Unlike adults, children are often unaware that their vision is impaired and therefore do not seek help. Furthermore, the lack of general awareness of the importance of vision tests, the inadequate numbers of trained personnel to conduct screening, and the costs of thorough testing, all work to the childrens' disadvantage, especially since the benefits of the screening are not directly reaped by the agencies typically funding the screening.

Vision screening is important, but currently it is not done comprehensively or very well. Preschool vision screening is especially underdeveloped despite several recent initiatives; for example, Head Start projects reported screening 680,000 children in 1968, and the National Society for the Prevention of Blindness reports that in the 1963-64 school year there were some 86 preschool screening projects working with 52,000 children, and in the 1964-65 school year there were some 290 projects screening 156,000 children. This is an encouraging trend, but the number of preschoolers screened is still a small fraction of the total.³⁶ For the sake of contrast, it was estimated that in 1970 some 12,500,000 children aged 5 to 17 had eye conditions requiring special care, or about one of every four children.³⁷ Of course, not all of these children are severely enough impaired to be called handicapped, but they still benefit from an identification program, for example, by finding out that corrective lenses are required and subsequently learning more in school.

³⁴ Gabriel Stickle, "What Priority Human Life?" *American Journal of Public Health*, November 1965, pp. 1692-1698, makes these points.

³⁵ Amitai Etzioni, "Mixed Scanning: A 'Third' Approach to Decision Making," *Public Administration Review*, December 1967, pp. 385-392, explains the general concept.

³⁶ Jane S. Lin-Fu, *Vision Screening of Children*, Department of Health, Education and Welfare, Health Services and Mental Health Administration, Maternal and Child Health Service, Washington, D.C., 1971. This is an excellent, concise work on the general topic.

³⁷ See Rand Report R-1220-HEW, Appendix A, and Department of Health, Education and Welfare, Social and Rehabilitation Service, Children's Bureau, *Health of Children of School Age*, Publication 427, Washington, D.C., 1964.

It is hard to determine the prevalence of preschool vision problems, but we know that rates of referral from preschool vision tests have ranged from 1 to 30 percent in sample programs.³⁸ Rules of thumb indicate that refractive errors account for 70 to 75 percent of these referrals, muscle imbalance about 20 percent, and amblyopia ("lazy eye disorder") about 10 percent.³⁹ But these figures are no more than partial approximations of the actual needs of the total preschool population, needs which are not reliably known and met with services because the identification measurements are not being made. Trying to answer more specific questions about important subsets of the total preschool population is even more difficult. For instance, we know that multiply handicapped children as a class have more visual problems,⁴⁰ but precise prevalence rates are not known for specific combinations of impairments. Furthermore, it is often harder to screen and diagnose these especially handicapped children, but not much effort has been expended in designing and testing specialized instrumentation and procedures to serve them.⁴¹

With identification through vision screening, the child has taken a necessary first step toward receipt of other services. The screening may, for example, result in referral of the child to a physician for a complete eye examination, and later to other personnel for sensory aids; it may make teachers aware of their students' eye conditions after diagnosis and service are rendered; or it may suggest possible service (e.g., for a child with corrected acuity of 20/70 or less) by a special education program. Screening is *not* diagnosis; it corresponds to the "awareness" phase of the identification process.

Basically, there are screenings by clinical history and screenings by vision tests.⁴²

Vision Screening by Clinical Histories

Studies indicate a correlation between those who fail vision tests and those who either have a family history of eye problems or have demonstrated signs and symptoms of visual disorder. Clinical histories are valuable and important screening devices, although many identification programs do not compile them. It is no great task to extract the portion of a clinical history relevant to eye disorders; it comprises several simple components, such as the following:

- Is there a family history of visual problems?
- What was the mother's pregnancy history, including the possibility that she might have had rubella, toxoplasmosis, syphilis, or toxemia?
- What was the birth history?

³⁸ J. W. Oberman, "Vision Needs of America's Children," *The Sight-Saving Review*, Vol. 36, Winter 1966, pp. 217-227.

³⁹ E. M. Hatfield, "Progress in Preschool Vision Screening," *The Sight-Saving Review*, Vol. 37, 1967, pp. 191-207.

⁴⁰ M. C. Fletcher and M. M. Thompson, "Eye Abnormalities in the Mentally Defective," *American Journal of Mental Deficiency*, Vol. 66, September 1966, pp. 242-244; Michigan Department of Public Health, *Vision and Hearing Screening in Selected Classes for the Mentally Retarded, City of Detroit, Michigan*, U.S. Department of Health, Education and Welfare, Social and Rehabilitation Service, Children's Bureau, Washington, D.C., 1966; and W. S. Schachat et al., "Ophthalmologic Findings in Children with Cerebral Palsy," *Pediatrics*, Vol. 19, April 1957, pp. 623-628.

⁴¹ For general referral guidelines see R. B. Kugel, "Vision Screening of Preschool Children," *Pediatrics*, Vol. 50, December 1972, pp. 966-967, in which the following criteria for referral are recommended: (1) 3-year-olds with 20/50 acuity or less, (2) 4-to-5-year-olds with 20/40 acuity or less, (3) differences in two eyes of 20 or more, and (4) strabismus. Failing any of these, it is argued, is reason to retest before referral.

⁴² Lin-Fu, op. cit., pp. 5-7.

- Were there neonatal problems, e.g., respiratory difficulty and the use of oxygen therapy?
- Are other handicapping conditions present?

Any significant positive findings should alert screening personnel to the increased odds that the child may have visual problems.

Signs and symptoms that often indicate visual problems include patient-supplied information about headaches, dizziness, sensitivity to light, and blurred vision, or observable signs such as crossed eyes, turned-out eyes, rapid eye movement (nystagmus), red, swollen, or puffy eyelids, watery eyes, and haziness in the pupils.

Behavior may also be indicative. Excessive blinking, squinting, rubbing, inattention to the blackboard, poor alignment in written material, holding books too near or far from the face, and poor performance in motor activities are all potential signs of trouble. Teacher and parent observations can be important, but they often appear to be overlooked or dismissed.

Preschool Vision Screening

The literature on vision screening of preschoolers is sometimes vague and inconsistent, and raises questions, while answering others.⁴³

The general purpose of existing preschool vision screening programs relates mainly to the "Awareness" phase of the identification model developed earlier. The primary aim of these programs is to detect the existence of low-vision problems.⁴⁴ Problems of refraction, general development, and medical diagnosis are all relatively neglected with respect to this age group.⁴⁵

A vision problem often cited as the object of preschool screening programs is amblyopia ex anopsia ("lazy eye blindness"). Treatment for it should not be delayed, as it may result in some permanent impairment of visual ability—impairment that is often avoidable if detected and treated at an early age.⁴⁶

All that is attempted in most preschool tests is the detection of abnormal distance acuity, and if detected, there is some presumption that the child will be directed to competent professional examination and treatment—a presumption not guaranteed by routine or formal institutional devices.

For infants, most tests are reflex-oriented. If a stimulus provokes some expected response, it is assumed that the visual pathways are working. Reaction of the pupils to light, aversion of the eyes in a lateral direction in the opposite direction of that

⁴³ A sampling of some of the more satisfying of the general literature follows: O. Ffooks, "Vision Test for Children, Use of Symbols," *British Journal of Ophthalmology*, Vol. 49, June 1965, pp. 312-314; R. H. Bock, "Vision Screening for Infants," *Ophthalmologic Supplement*, Vol. 47, 1957; B. H. Schwarting, "Testing Infants' Vision-Apparatus for Estimating Visual Acuity of Infants and Young Children," *American Journal of Ophthalmology*, Vol. 38, 1954; H. F. Allen, "Testing Visual Acuity in Preschool Children," *Pediatrics*, Vol. 19, 1957; and J. N. Evans, "Visual Tests for Infants," *American Journal of Ophthalmology*, Vol. 29, 1946.

⁴⁴ Oberman, op. cit.

⁴⁵ The important work of A. Gesell, "Developmental Aspect of Child Vision," *Journal of Pediatrics*, Vol. 35, 1949, is a notable exception. See also R. W. Lowry, Jr., *Preschool Vision: Tests, Diagnosis, Guidance*, The American Optometric Association, St. Louis, Missouri, 1959, which is another valuable source.

⁴⁶ T. Gundersen, "Amblyopia ex Anopsia: A Preventable Form of Blindness," *Pediatric Clinics of North America*, Vol. 2, No. 2, 1955; C. W. Lepard, "Early Diagnosis of Visual Impairment in Children," *Postgraduate Medicine*, Vol. 24, 1958; R. W. Dockery, "The Value of Vision Screening in the Preschool Age Child," *Journal of the National Medical Association*, Vol. 52, 1960; D. Vaughn et al., *Eye Tests for Preschool and School Age Children with Special Emphasis on the Detection of Amblyopia ex Anopsia in Preschool Children*, California Medical Eye Council, Stockton, California, 1960; and O. Lippmann, "Vision of Young Children," *Archives of Ophthalmology*, Vol. 81, June 1969, pp. 763-775.

in which the infant's head is quickly turned (doll's eyes phenomenon), and response to a moving series of lines are all possible screening tests. Other reflex-oriented tests can also be used if the examining physician or nurse is alerted to the possible presence of visual problems and trained to perform them.⁴⁷

For children from about age 1 to 2 years, subjective tests have been used.⁴⁸ Walking infants are asked to retrieve small, standardized objects from varying distances with each eye covered in turn. If the child can talk, several other tests can be used: picture tests,⁴⁹ direction tests,⁵⁰ and some very specific acuity tests.⁵¹

Medical examinations by pediatricians and general practitioners could be much more effective than they are, in practice, in the early detection of preschool visual problems. For instance, in a section of a standard pediatric textbook devoted to "Examination of the Pediatric Patient," Kempe and his colleagues recommend the following to the pediatrician:⁵²

Most newborns have the visual capacity to fix on a moving object as early as the first few minutes of life. Infants who do not follow a face at the first well child visit should be suspected of having a visual problem. Ophthalmoscopic examination should be done on one of the earliest possible visits in order to make the diagnosis of cataract, congenital glaucoma, or retinal abnormality.

And later in this same section:

Five to 10 percent of preschool children have some kind of visual impairment. The illiterate E chart, Snellen chart, or Allen cards can be used for checking visual acuity, and each eye should be tested separately. The 5-year-old child should have a visual acuity of 20/30 or better in both eyes, and there should be no significant difference between the two eyes. Amblyopia ex anopsia affects 2 to 5 percent of children and must be detected early before permanent loss of vision occurs.

In a subsequent section of Kempe devoted entirely to the pediatric eye, Ellis comments about the important and underutilized role of the mother in performing preschool visual acuity tests:

Routine testing of visual acuity should be a part of every general physical examination. It is the single most important test of visual function. In

⁴⁷ Frank W. Newell, *Ophthalmology: Principles and Concepts*, C. V. Mosby, St. Louis, Missouri, 1969 ed., pp. 90-91. Dr. J. Terry Ernest pointed this out in an interview with G. D. Brewer, Chicago, Illinois, March 1972.

⁴⁸ Many of which are noted in E. S. Duke, *Textbook of Ophthalmology*, C. V. Mosby, St. Louis, Missouri, 1971; and Vaughn et al., op. cit.

⁴⁹ G. Osterberg, "A Sight-Test Chart for Children," *Acta Ophthalmology*, Vol. 14, January 1936, pp. 397-405; and C. Berens, "Visual Acuity and Color Recognition Tests for Children," *American Journal of Ophthalmology*, Vol. 46, 1958.

⁵⁰ A. E. Sloane and J. R. Callagher, "A Vision Test for Pediatricians' Use," *Journal of Pediatrics*, Vol. 28, 1946. The child is asked to point out the direction in which some object is facing, heading, etc. See also S. D. Liebman and S. S. Gellis (eds.), *The Pediatrician's Ophthalmology*, C. V. Mosby, St. Louis, Missouri, 1966.

⁵¹ E.g., "STYCAR" tests ("Screening Tests for Young Children and Retardates"); see M. D. Sheridan, "Vision Screening of Very Young or Handicapped Children," *British Medical Journal*, Vol. 2, 1960; and idem, "Vision Tests for Young Children, Normal and Handicapped," *Spastics Quarterly*, Vol. 11, March 1962, pp. 25-33.

⁵² C. Henry Kempe et al., *Current Pediatric Diagnosis and Treatment*, Lange Medical Publications, Los Altos, California, 1972, pp. 124-125. The following are visual acuity tests in current usage for preschoolers: Snellen E Test, Sjogren Hand Test (like the Snellen but uses hands and fingers), Landolt Broken Ring Test (variation of Snellen), California Clown Test—"Do-As-I-Do Vision Test" (another variation of the Snellen), matching letters tests, picture tests, symbol tests, miniature toy tests, etc. The

children 4 years old or older, satisfactory visual acuity tests can usually be obtained with the use of Snellen test cards or illiterate E charts. . . . The mother, with her interest, can repeat the test at her leisure, and the final result is usually more accurate than testing done in the office by the pediatrician or his nurse.⁵³

With respect to mass screening, several problems confront those interested in complete and reliable coverage of the preschool population.⁵⁴ Besides the general observation that there is no existing formal institutional mechanism to guarantee that the child will be screened before entering school, a problem noted previously, difficulties are reported in even those few instances where special efforts have been made to carry out these tests.

Screening tests themselves have not been standardized and misidentifications are not uncommon, or at least this seems to be the general point raised in several case settings where preschool vision testing has been tried on a large scale.⁵⁵ Given the problems with test standardization, variation in the criteria used for referral, and the absence of reliable information on rates of clinical referral and follow-up, it is difficult to say much about any of the following points—all of which are necessary inputs and factors to be considered before making any recommendations about mass screening for preschoolers:

- The quality of screening techniques to be used;
- The expected incidence and referral rates for various kinds of visual disorder;
- The cost of a mass screening program for preschoolers;
- The magnitude of the benefits that might accrue to the overall population as a result of such an undertaking.

In light of critical unresolved questions, especially concerning whether potential benefits of mass screening of all children at a preschool age rather than age 5 outweigh the costs, we do not recommend *mass* screening for visual impairment in the *preschool* population. Rather, the value of the pediatrician and the family in the identification process is such that we have chosen to concentrate attention on them instead.

It has been noted that on the average parents are excellent diagnosticians, but that parental anxiety is often⁵⁶

compounded by professional denial of the diagnosis or by false reassurance. One-third of the parents interviewed by Meadow⁵⁷ and seen by Schlesinger. . . indicate that the first physician consulted denied the suspected deaf-

point of this lengthy description is to show that it is not for want of instruments that preschool vision testing is not conducted.

⁵³ Philip P. Ellis, "Eye," in *ibid.*, pp. 197f.

⁵⁴ Apell and Lowry, *op. cit.*, and Hatfield, *op. cit.*

⁵⁵ D. M. Hufhines, "Preschool Vision Screening in Orange County, California: I. Community Organization," *The Sight-Saving Review*, Vol. 31, 1961, pp. 210-214; E. L. Russell, J. M. Kada, and D. M. Hufhines, "Orange County Vision Screening Project: II. Ophthalmologic Evaluation," *ibid.*, pp. 215-219; Michigan Department of Public Health, *op. cit.*; *idem*, "Preschool Hearing, Vision Training Results Revealed," *Michigan Medicine*, Vol. 64, 1965; T. M. Colasuonno, *Preschool Vision Screening in Douglas County, Oregon*, National Society for the Prevention of Blindness, Publication P-255, New York, n.d., and *idem*, *Preschool Vision Screening in Louisville*, National Society for the Prevention of Blindness, Publication P-254, New York, n.d.

⁵⁶ Hilde S. Schlesinger, "Diagnostic Crisis and its Participants," in Arthur G. Norris (ed.), *Deafness*, Vol. II, Professional Rehabilitation Workers with the Adult Deaf, Inc., Silver Spring, Md., 1972, pp. 29-34, at p. 30.

⁵⁷ K. P. Meadow, "Parental Responses to the Medical Ambiguities of Deafness," *Journal of Health and Social Behavior*, Vol. 9, 1968, pp. 299-309, as cited in *ibid.*

ness. Sixty percent of the parents in Meadow's study consulted four or more physicians prior to receiving a definite, accurate diagnosis.

One of the reasons that early diagnosis is often not accomplished is that physicians generally and pediatricians particularly are not well and thoroughly trained to detect early childhood hearing and vision disorders.

The pediatrician has a serious responsibility with respect to identifying all types of physical and mental handicaps in children, and he would be aided in discharging that responsibility if:

- Authorities responsible for medical school curricula would review those aspects devoted to pediatric examination to insure that this material is covered and receives the serious attention it warrants;
- State boards certifying pediatricians would examine applicants to call attention to this responsibility and to insure that certified pediatricians know how to conduct screening procedures for the various handicapping conditions appropriate for the age and general condition of the pediatric patient;
- Those responsible for pediatric residency programs would review their programs to insure that both aural and visual screening procedures are learned and routinely carried out. If necessary, formal communication with ophthalmologic (and otolaryngologic) services could be instituted to guarantee the quality of the instruction.

The parent's close contact with the preschooler should be exploited far more than it has been in the past. A parent may perform periodic initial screening of the preschooler at home as well as or better than would a massive, one-shot program.⁵⁸ The child is more relaxed, the mother has more time to carry out the basic tests and to repeat them until she gets stable results, and she has specific knowledge about the child that no one-time screener could be expected to match. Parents would be aided if:

- Programs such as that being conducted by the National Society for the Prevention of Blindness noted earlier were encouraged, evaluated as to effectiveness and cost, and then expanded if warranted; and
- Parallel activities were supported to explore alternative testing instruments, practices, and corresponding results when parents test the preschool child in their home.

Finally, the nursery school—an expanding trend associated with heightened interest in early childhood education—is another underused resource. In this case the teacher and school nurse (if one is available) could be trained to recognize behavioral cues and perform screening. Again, this is not diagnosis; it is intended to pick up the grossest of sensory deviance as early as possible so that the child *suspected* of having problems may be identified and given professional diagnosis. The importance of follow-up and direction are critical and obvious in this case.

- Where procedures to license and certify preschool nursery personnel exist, we recommend that efforts be made to instruct and sensitize those personnel to be alert to the possible presence of sensory problems.

⁵⁸ R. A. Savitz, T. Valadian, and R. B. Reed, "Vision Screening of Preschool Children at Home," *American Journal of Public Health*, Vol. 55, October 1965, pp. 1555-1562; R. R. Trotter, R. M. Philips, and K. Shaffer, "Measurement of Visual Acuity of Preschool Children by Their Parents," *The Sight-Saving Review*, Vol. 36, Summer 1966, pp. 80-87; and E. Press and E. Austin, "Screening of Preschool Children for Amblyopia: Administration of Tests by Parents," *Journal of the American Medical Association*, Vol. 204, May 27, 1968, pp. 767-770.

- We recommend that clear standards and procedures of reporting suspected sensory problems to parents and health and education authorities be created (where none currently exist) or reviewed and improved (where they do exist).

School-Age Vision Screening

Carefully controlled studies of the reliability of the available school vision screening tests and programs have not been done routinely or on a national comparative and evaluative scale.⁵⁹

In those cases that have been monitored to some extent,⁶⁰ a number of consistent findings emerge:

- The programs are relatively expensive.
- Good screening programs, as measured solely by high rates of confirmation of true positives by diagnosticians, have trained and certified visual-technical specialists either closely supervising or actually conducting the tests.
- Something on the order of 10 percent should be expected to “fail” the school vision screening programs, although the prevalence rates of disorders contributing to this rule of thumb are not well or reliably reported.
- Follow-up is a critical component in those programs thought to be relatively effective. That is, parents need to be informed of possible visual problems, they need encouragement and information about where to get competent diagnostic help, they may need financial assistance in obtaining the service, e.g., glasses and medical treatment, and they may need reminders to have the child examined further.

The State of Michigan has amassed a commendable record in its school vision program over the last 30 to 35 years.⁶¹ As reported, this program is straightforward in its design and implementation and could serve as a model for vision screening programs at the school level in other locations. Generally characterized as benefiting from good public education, high standards of personnel doing the testing, sound administration, and persistent follow-up procedures, the Michigan program has enjoyed confirmed true positives averaging around 90 percent over the years—a remarkable achievement. One result is that physicians respect the program and take its referrals seriously. Some 200 “vision technicians,” employees of the Maternal and Child Health Division of the Michigan State Department of Public Health, have been recognized and suitably appreciated by public and policymaker alike as the essential ingredient in the program’s success. The second key element is the administrative procedures of follow-up, created to insure that the identification process does not break down before needed services are delivered. A notification is mailed to the parents when a child is found to have a vision problem. The notification includes a blank doctor’s report that the parents are asked to have filled out and returned to the Department of Public Health. If no report is received within six

⁵⁹ National Society for the Prevention of Blindness, *Vision Screening in Schools*, Publication 257, New York, 1961; and E. B. Guttman, “School Vision Screening,” *The Sight-Saving Review*, Vol. 26, Winter 1956, pp. 212-219.

⁶⁰ A. E. Sloane and R. A. Savitz, “Vision Screening,” *International Ophthalmology Clinic*, Vol. 3, December 1963, pp. 803-809; Henrik L. Blum et al., *Vision Screening for Elementary Schools: The Orinda Study*, University of California Press, Berkeley, 1959; A. E. Sloane and P. Rosenthal, “School Vision Testing,” *Archives of Ophthalmology*, Vol. 64, November 1960, pp. 143-150; and N. B. Belloc, “Vision Screening in the United States,” *The Sight-Saving Review*, Vol. 32, No. 4, Winter 1962.

⁶¹ Blackhurst and Radke, op. cit., and Michigan Department of Public Health, *Vision and Hearing Screening*.

weeks, a follow-up letter is sent and the child's school nurse is notified. On their own initiative, Department personnel might then get in touch with the parents to inform them of local diagnostic services.

For school age children we recommend that:

- Various apparently successful programs, including the Michigan model, be thoroughly evaluated for full details of their operation, costs, and benefits;
- A reproducible model or models for other states be developed, given the detailed findings of those thorough evaluations, which could serve for a full-scale implementation throughout the country; and
- A comprehensive mass vision screening program be instituted throughout the United States, designed to reach every school-age child.

Importance of Hearing Identification

Serious and permanent hearing deficits occur in slightly more than 1/2 percent of the children, or about 490,000, aged 0 to 21; and for 10 percent of this group of handicapped children, their loss is profound and bilateral, resulting in a nonfunctional sense of hearing.⁶² About 10 percent of all children have less severe but still significant hearing impairment (15 + dB).⁶³ The most frequent cause of children's hearing loss is recurrent chronic otitis media or serous otitis media (infections of the middle ear).⁶⁴ Even children with a single episode of otitis media may have some degree of hearing impairment for some period after the acute episode.

Although these hearing losses may not be too severe, they may occur at an unfortunate time and may be sufficient to inhibit the acquisition of language⁶⁵—a setback that may affect the child throughout his school years.⁶⁶ If the losses are discovered and services provided before school begins, many of the learning, behavioral, and discipline problems that ensue from poor hearing and poor attention may be averted.

Detection of such problems is as much a part of preventive pediatrics as is the immunization routine. Audiologic screening tests can be performed by nonprofessional technicians and should be a part of the preschool examination.⁶⁷

⁶² See Rand Report R-1220-HEW, Appendix A, for details.

⁶³ D. Ling, "Early Identification and Epidemiology of Hearing Disorders," *Rehabilitation Digest*, Vol. 8, No. 1, 1971, pp. 5-9, at p. 6.

⁶⁴ V. Holm and L. Kunze, "Effect of Chronic Otitis Media on Language and Speech Development," *Pediatrics*, Vol. 43, May 1969.

⁶⁵ G. Bekesy, "Current Status of Theories of Hearing," *Science*, Vol. 123, 1956, pp. 779-783; J. B. Carroll, *The Study of Language*, Harvard University Press, Cambridge, 1953; C. P. Goetzinger, "Effects of Small Perceptual Losses on Language and on Speech Discrimination," *Volta Review*, Vol. 64, 1965; and James E. Kavanagh, *The Genesis and Pathogenesis of Speech and Language*, National Institute of Child Health and Human Development, Department of Health, Education and Welfare, Publication NIH 72-36, Washington, D.C., 1971.

⁶⁶ Lois L. Elliott and Ann B. Vegely, "Some Possible Effects of the Delay of Early Treatment of Deafness: A Second Look," *Journal of Speech and Hearing Research*, Vol. 11, December 1968, pp. 883-886; Lois L. Elliott and V. B. Armbruster, "Some Possible Effects of the Delay of Early Treatment of Deafness," *ibid.*, Vol. 10, 1967, pp. 209-224; M. M. Lewis, *Language, Thought and Personality in Infancy and Childhood*, Basic Books, New York, 1963; and A. R. Luria and F. Yudovich, *Speech and the Development of the Mental Processes in the Child*, Staples Press, London, 1966.

⁶⁷ Kempe et al., *op. cit.*, p. 125; see also G. L. Wyatt, "Speech and Language Disorders in Pre-School Children: A Preventive Approach," *Pediatrics*, Vol. 36, 1965.

Characteristics of Hearing Loss in the Youth Population

While the importance of early identification of hearing handicapped youth is undeniable, we know little about the characteristics of that population until they are about age 5 and over.

There are several types of hearing loss. *Sensorineural hearing loss* (or "nerve deafness") is due to a problem within the inner ear, in the nerves going from the inner ear to the brain, or in the brain itself. The loss may result from infection, trauma, toxic substances, degenerative disease, or congenital causes (see Chapter 5). *Conductive hearing loss* occurs in patients with a normal inner ear who are hard of hearing because something is wrong with the mechanism conducting the sound to the inner ear. Medical or surgical procedures, or amplification, may restore hearing partially or fully in such cases. *Congenital deafness* is probably present at birth or occurs soon thereafter. *Mixed hearing loss* involves both conductive and neural components. And *simulated hearing loss* results from causes that cannot be traced to organic disease, as in instances of involuntary, e.g., emotional or psychotic, disorders.⁶⁸

Typically, hearing loss found in school audiometry programs is slight, conductive (not sensorineural), and transient (not permanent).⁶⁹ In urban schools, between 2 and 5 percent of children may require referral to physicians for medical attention and diagnosis.⁷⁰

Most children with sensorineural loss are "hard of hearing" rather than deaf. This means that many of them can benefit greatly from hearing aids, despite the aural distortion that often occurs with this type of impairment. Sensorineural hearing loss usually occurs early in life and prevents or hinders the natural development of speech and language. Early diagnosis and treatment, together with effective teaching methods, could do much to reduce the total degree of functional handicap resulting from this type of hearing loss.

Measurement of Hearing

The current state of hearing measurement is relatively well developed and diverse, and is represented in a large and growing literature.⁷¹

Using an audiometer, the basic instrument, a competent audiometrist can test hearing by using air and bone conduction techniques. Hearing losses in children have been identified and measured at virtually all ages, with the possible exception of the first months of life. The younger the child, naturally, the more sophisticated must be the instrumentation and the measurement specialist. This relates directly to our concept of the general identification process, in that gross screening ("awareness") tests may be done by a nurse or pediatrician in the office or nursery to pick up suspected hearing loss; solid diagnosis must be done where experience, specialized skill, and instrumentation are all more developed.

⁶⁸ David D. DeWeese and W. H. Saunders, *Textbook of Otolaryngology*, C. V. Mosby, St. Louis, Missouri, 1968, pp. 275-276.

⁶⁹ E. L. Eagles, S. M. Wishik, and L. G. Doerfler, "Hearing Sensitivity and Ear Disease in Children," *Laryngoscope Monograph*, 1967.

⁷⁰ D. Ling, "Early Identification and Epidemiology of Hearing Disorders," *Rehabilitation Digest*, Vol. 8, No. 1 1971, pp. 5-9; see also S. R. Silverman, "Clinical and Educational Procedures for the Deaf," in L. Travis (ed.), *Handbook of Speech Pathology*, Appleton-Century-Crofts, New York, 1957, p. 398.

⁷¹ DeWeese and Saunders, op. cit., pp. 275-298; J. J. O'Neill and H. J. Oyer, *Applied Audiometry*, Dodd, Mead, New York, 1966, contains a technically detailed and thorough survey of the methods; A. Glorig (ed.), *Audiometry: Principles and Practices*, Williams and Wilkins, Baltimore, 1965, and I. M. Ventry and J. B. Chaiklin (eds.), "Multidiscipline Study of Functional Hearing Loss," *Journal of Audiological Research*, Vol. 5, 1965, pp. 179-262, have a comprehensive and detailed program that merits consideration.

Ideally, screening tests should be done at birth and at all pediatric examinations so that possible hearing losses are picked up as early as possible. While this study is narrowly interested in children having hearing losses of about 40 dB and more, it is also important that children with lesser deficits of, say, 15 to 40 dB be identified so that parents and teachers can seek more specialized help if required. Rehabilitation can begin as early as the deficit is detected, which generally means as early as 6 months of age.⁷²

Competent audiometrists are critical in the screening process. Ballenger enlarges on what constitutes "competency" here in the following terms:

Adequate audiometry cannot be carried out by personnel who have not received suitable training and experience. In order to obtain accurate and useful clinical information, the audiometrist must have a satisfactory grasp of the basic principles underlying behavioral measurement. He must, in addition, be familiar with the audiologic patterns associated with the various types of hearing disorders. Finally, he must understand the limitations of electroacoustic instruments.⁷³

Air conduction audiometry measures the sensitivity of the entire hearing system by placing an oscillator-driven earphone over the external ear. Because response derives from the entire hearing system, one is generally not able to isolate the point of hearing loss, if there is one.

Bone conduction audiometry measures the sensitivity of the sensorineural mechanism by placing a stimulus (tuning fork, bone conductor vibrator) directly to the patient's skull. So doing short-circuits the transmission mechanisms of the middle ear, and helps to determine the type of hearing loss.

Hearing loss of 15 dB or more is one standard reference point for referral. Patients with that much loss should be considered candidates for special attention and services.⁷⁴

Congenital deafness has been detected in infancy by exposing the child to acoustic stimuli and then recording his responses. Infants with significant hearing loss have been successfully fitted with hearing aids at one month of age.

The importance of taking the relevant clinical history as a routine part of the hearing screening process is as great here as it is for vision screening. Positive relationships exist between failures on hearing tests and family histories of ear disorder or those who have demonstrated signs and symptoms of hearing disorder. While this relationship is well known, the taking of clinical histories is not always a routine part of the child's hearing screening program. For example, audiologic high-risk registries (composed of those singled out in the clinical history process) have been important in detecting hearing losses in children as young as 6 months old. Without such registries, the earliest time that hearing loss is detected is commonly around 20 months.⁷⁵

Testing very young children calls for patience and no little ingenuity. They have little reason to want their ears tested, they often fear strangers and unnatural

⁷² Marlin Weaver and Marion P. Downs, "Ear, Nose, and Throat," in Kempe et al., op. cit., pp. 221-245. For a general survey of the diagnostic literature, see L. M. Di Carlo et al., "Diagnostic Procedures for Auditory Disorders in Children," *Folia Phoniatica*, Vol. 14, 1964, pp. 206-264.

⁷³ John Jacob Ballenger et al., *Diseases of the Nose, Throat, and Ear*, Lea and Febiger, Philadelphia, 1969 ed., pp. 581-599, at p. 581.

⁷⁴ Howard P. House, F. W. Linthicum, Jr., and E. W. Johnson, "Current Management of Hearing Loss in Children," *American Journal of the Disabled Child*, Vol. 108, 1964, pp. 677-696; and A. Miller and L. Newburg, "Infant Orientation to Hearing Aids: A New Approach," *American Journal of the Disabled Child*, Vol. 113, 1967, pp. 466-468.

⁷⁵ Kempe et al., op. cit., pp. 124-125.

settings, it takes special effort to get them to listen attentively to sounds, and their responses are none too accurate. Finally, the child may not know what he has been missing, unlike the adult who may have enjoyed good hearing in the past. The very young child's deficit probably has been with him since birth and seems perfectly "normal" to him, in a real sense of that term.⁷⁶

To restate the main point of much of this discussion, it is generally agreed that early detection and treatment of hearing loss are crucially important.

Every physician who is responsible for the care of infants should develop similar screening programs in the hospital nursery or at least check the infant's hearing at the first visit by the use of squeak toys and bells which have as close to pure tone sounds as possible. The newborn will only respond by a flicker of his eyelids or a very minute Moro response [body tremor in response to aural stimulus.]⁷⁷

Preschool Hearing Tests

Most 4-year-olds can be tested with conventional techniques. Children younger than 4, including the newborn, may also be tested with a variety of techniques, although diminished reliability and increased cost are to be expected. Davis and Silverman, for instance, divide hearing tests for the very young into three general classes: methods based on increased motivation, physiological audiometry, and electrophysical tests.⁷⁸

The first class includes "games" and other devices designed to capture and maintain the child's interest in a conventional audiological examination. Children over 2-1/2 years old normally play games and hence can be tested with these methods. The second class of tests depends on behavioral reactions of the child, e.g., startle reactions, reflexes, awakening from sleep, and movements toward or away from a sound stimulus—the last of which, "orienting reactions," are thought to be the "best in the critical period from 6 to 12 months of age when identification and approximate assessment of impaired hearing are so important."⁷⁹ The third class is generally not suitable for mass screening at the current state of development, because of the size, cost, and demand for very specialized skills and instrumentation. As diagnostic aids, however, the third class is important; it includes electrodermal audiometry (galvanic skin responses to sound stimuli), electroencephalic audiometry (EEG patterns are assessed with respect to various sounds), and electric response audiometry (evoked response audiometry). These assessment techniques are known fairly well in the specialized audiologic community, but their administration is dependent upon earlier, grosser recognition that the child has some hearing impairment.⁸⁰ In terms of the identification model developed earlier, tests of the third class would clearly fall into the "Diagnosis" phase.

Given the fact that a large number of children are examined only at birth when identification is difficult, and then not again until their school entrance examinations, the need for some kind of preschool age identification program is clear, as is

⁷⁶ Ballenger et al., op. cit.

⁷⁷ Kempe et al., p. 125; see also R. Carhart and J. Jerger, "Preferred Method for Clinical Determination of Pure-Tone Thresholds," *Journal of Speech and Hearing Disability*, Vol. 24, 1959, pp. 330-345; and H. Newby, *Audiology*, Appleton-Century-Crofts, New York, 1958.

⁷⁸ Hallowell Davis and S. Richard Silverman (eds.), *Hearing and Deafness*, Holt, Rinehart, and Winston, New York, 1970 ed., pp.237-248.

⁷⁹ *Ibid.*, p. 240.

⁸⁰ R. B. Eisenberg, "Auditory Behavior in the Human Neonate, I. Methodological Problems and the Logical Design of Research Procedures," *Journal of Audiological Research*, Vol. 5, 1965, pp. 159-177.

the need for physicians (especially pediatricians) to be alert for hearing problems during routine check-ups.⁸¹

Hearing Tests at Various Ages of the Young

Screening At Birth. There is a very large literature on screening at birth; its main points can be summarized as follows:

- It can be done but it depends on the skill and training administered to screening personnel, e.g., nursery nurses who repeat simple reflex tests over the entire period that the newborn is in the hospital.⁸²
- Responses are not too reliable. Both false positives and false negatives are commonplace. The need for repeated testing is clear.
- Based on the experimental evidence, mass screening techniques of the newborn are not reliable enough for consideration for large-scale implementation.⁸³

This does not mean that efforts should be abandoned to develop better ways to conduct mass screenings at birth; it merely affirms that current testing methods and procedures are not sufficiently reliable.⁸⁴ A promising innovation is the recently reported "Crib-o-gram" system developed by Blair Simmons and his colleagues at the Stanford Medical School,⁸⁵ a full-scale evaluation, including follow-up of the identified children as they age, will be needed to confirm its value.

A recent summary by Bordley and Hardy advances the following comments about neonatal hearing screening—comments justified by a thorough review of the literature:

Neonatal auditory screening appears to bear no relationship to subsequently identified hearing loss; in fact, 98 percent of the 248 children failing the audiometric test at age 8 years gave normal responses to sound stimuli of 65 dB to 75 dB during the newborn period. These findings are in accord with our past experience.⁸⁶

⁸¹ *Conference on Newborn Hearing Screening*, Department of Health, Education and Welfare, Public Health Service, Maternal and Child Health Service, Washington, D.C., 1971.

⁸² Jean Robinson, "Screening Techniques in Babies," *Sound*, Vol. 4, No. 4, 1970, pp. 91-94; and Rayford C. Redell and Donald R. Calvert, "Factors in Screening Hearing of the Newborn," *Journal of Auditory Research*, Vol. 3, 1969, pp. 278-289.

⁸³ Marion P. Downs, "The Identification of Congenital Deafness," *Transactions of the American Academy of Ophthalmology and Otolaryngology*, Vol. 74, 1970, pp. 1208-1214, tends to support this pessimistic assessment after reviewing the available evidence.

⁸⁴ The use of high-risk registries, for example, has been instrumental in narrowing the total population down to a more manageable subset of those likely to have hearing difficulties. For this group, every and all screening techniques would appear to be warranted. L. Bergstrom, W. G. Hemenway, and Marion P. Downs, "A High Risk Registry to Find Congenital Deafness," *Otologic Clinic of North America*, Vol. 4, 1971, pp. 369-399; and Marion P. Downs, "Audiologic Evaluation of the Congenitally Deaf Infant," *Otologic Clinic of North America*, Vol. 4, 1971, pp. 347-358.

⁸⁵ Basically, the movement of the child is carefully and automatically recorded in response to aural stimuli. "Abnormal" responses signal that the baby may have some hearing difficulties and indicate that the physician should administer more intensive diagnostic procedures. It has been reported in the press that some 6000 babies have been screened with the Crib-o-gram system since 1970 and 300 "failures" were identified, of whom 8 were actually shown to have hearing loss in subsequent diagnostic workups. *Los Angeles Times*, September 23, 1973, Part 1, p. 3.

⁸⁶ John E. Bordley and Janet B. Hardy, "A Hearing Survey on Preschool Children," *American Academy of Ophthalmology and Otolaryngology*, Vol. 76, No. 2, 1972, pp. 349-354, at p. 353. This study implicitly calls attention to the pressing need for follow-up evaluation of children as they pass through the 0-5 period to determine the true rates of false positive reports for those children who in fact have received one of the many neonatal tests. Follow-up has been sparse so far.

Another summary evaluation of the considerable literature on neonatal screening adds the following cogent comments:

- Mild hearing loss is not routinely detectable, and unilateral loss is not detectable.
- The absolute number of missed children does not appear to be large, but the question is somewhat moot given the condition of the existing data.
- Screening procedures are not very good. There are too many false positives caused by a conservative orientation of the testers, who do not want to let a hearing impaired child slip through, and by operational problems connected to test administration.
- Follow-up on identified children is either not done or is done by nonspecialists, with the result that the problem of parents laboring under false positive identification looms somewhat large.
- Economic arguments about relative benefits derived from special training at age 1 versus age 3 or 4 are not well established. [There is] "no evidence to prove that detection at age four days for example, followed by immediate guidance and training, leads to a significant financial savings compared to when detection is accomplished and training is begun at four weeks, four months, or even two or three years."⁸⁷

Screening at 0 to 2 Months. Gross overall response to sound stimuli predominate in the 0 to 2-month range.⁸⁸ Electroencephalographic techniques, which record the brain's electrical activity after sensory stimuli, appear to have promise, but have not yet been demonstrated to be sufficiently valid, and much work is still in the early developmental stage.⁸⁹ Simple observational differences between "normal" and hearing disabled children have been noted; and Kaye has discerned significant patterns of sucking behavior.⁹⁰ Only slightly more involved were studies measuring the latency periods between the instance of aural stimulation and the crying response. Profoundly impaired babies of course did not respond; partially hearing babies would either not respond, would respond at significantly lengthier latency rates, or would not respond in synchronization with the stimulus.⁹¹ Spectrographic analyses have been carried out that were reliably able to discriminate in the experimental setting between hearing and non-hearing babies.⁹² In the older 7-to-12 month range, cries having higher pitches, greater pitch variability, and variations in intensity produced characteristic and different spectrographic signatures for normal and disabled children.

Screening at 3 to 24 Months. Behavioral responses are observable by about

⁸⁷ Robert Goldstein and Charles Tait, "Critique of Neonatal Hearing Evaluation," *Journal of Speech and Hearing Disorders*, Vol. 36, No. 1, 1971, pp. 3-18, at p. 10.

⁸⁸ E. F. Waldon, "Audio-reflexometry in Testing Hearing of Very Young Children," *Audiology*, Vol. 12, 1973, pp. 14-20.

⁸⁹ Two fairly representative efforts are E. L. Lowell, "Electrophysiologic Tests of Hearing in Children," in E. H. Nober (ed.), *Trends in the Audiologic Assessment and Rehabilitation of Children*, Syracuse University Press, Syracuse, New York, 1967, pp. 41-50; and I. Rapin and L. J. Graziani, "Auditory-evoked Responses in Normal, Brain-damaged, and Deaf Infants," *Neurology*, 1967, pp. 881-894. See also V. Goodhill, "Deafness Research: Where Are We?" *The Volta Review*, Vol. 70, No. 8, 1968, pp. 620-629.

⁹⁰ H. Kaye, "The Effects of Feeding and Tonal Stimulation on Non-nutritive Sucking in a Human Newborn," *Journal of Experimental Child Psychology*, Vol. 3, 1966, pp. 131-134.

⁹¹ J. K. Cullen et al., "The Development of Auditory Feedback Monitoring: I. Delayed Auditory Feedback Studies on Infant Cry," *Journal of Speech and Hearing*, Vol. 11, No. 1, March 1968.

⁹² M. C. Jones, "An Investigation of Certain Acoustic Parameters of the Crying Vocalization of Young Deaf Children," Ph.D. thesis, Northwestern University, 1965 (University Microfilms, Ann Arbor, Michigan, 1965).

the second month;⁹³ the infant is capable of being distracted by and of paying attention to sound. By the age of 4 months, eye movement in response to stimuli should be observable. The average 1-year-old is able to comprehend sounds and recognizes his parents; and by about 18 months can identify parts of his body and favorite toys.⁹⁴ By approximately 18 months, two- or three-word sentences should be regularly produced. If these abilities are not manifest at approximately these stages, parents should seek professional assistance and diagnosis of suspected hearing loss. As we found in our parent interviews, however, parental suspicion is sometimes discounted by pediatricians as merely unnecessary anxiety. Judgment and sensitivity on the part of the physician is the key to identification in this early age period. Careful and consistent observation is called for by parents and doctors alike.⁹⁵

Several small-scale screening programs for children in this age group were found in the literature; however, none seems to have comprehensive applicability.

- Much of the population in this age group is not routinely seen by a physician (no existing institutional mechanisms guarantee adequate coverage).
- Visiting nurses have been used, but they are few, are not all adequately trained in this field, are often overworked, and are not in contact with the total population.
- Public health clinics, well-baby clinics, etc., are not ordinarily set up to conduct this kind of screening nor do they serve a majority of the population.
- Reliance on high-risk registries would appear to have particular appeal for coverage of this age group.

Screening at 24 Months to 5 Years. Screening is possible in this age range. By this time the child should be able to respond to sounds voluntarily. Simple tests can be performed by the physician, or even the parent if trained (see Table 4.1), and play-conditioning and finger-raising, both in response to commands, are commonly reported in the literature.⁹⁶ Failing these tests should be cause to seek out more competent diagnosis. The basic problems of doing screening for this age group have been summarized by Ballenger.⁹⁷

- Fear of strangers and strange settings;
- Fear of earphones;
- Learning about the expected stimulus response behavior inherent in most screening procedures (and thereby either volunteering response or failing to respond out of coyness or boredom);
- Maintenance of attention to the test.

Despite these problems, the benefits of early preschool identification of hearing handicapped youth appear large in relation to the costs. Among the benefits are reduction of the potentially permanent inhibition of language and speech development by medical or surgical treatment of the hearing loss, provision of sensory aids, and provision of preschool special educational services. Profoundly deaf and severely

⁹³ J. Koch, "Conditioned Orienting Reactions in Two-Month-Old Infants," *British Journal of Psychology*, Vol. 58, 1967, pp. 105-110.

⁹⁴ J. Medioni and R. Tronche, "A New Method for Diagnosing Deafness in Young Children," *Bull. Information*, Vol. 13, 1967, pp. 9-16, describes a pure tone test using toys as a reward mechanism.

⁹⁵ Ballenger et al., op. cit.

⁹⁶ Philip Lichtenberg and Dolores Norton, *Cognitive and Mental Development in the First Five Years of Life—A Review of Recent Research*, National Institute of Mental Health, Chevy Chase, Maryland, 1970; and Davis and Silverman, op. cit.

⁹⁷ Ballenger et al., op. cit., Chapter 41.

Table 4.1

SIMPLE CHART TO RATE HEARING

	Normal	Abnormal
Speech		
Does your child say a few words?	12-18 months	2 years and up
Can he say some words containing each of the following sounds? s (as in yes, bus, see, sock) sh (as in shoe, shut, fish) k (as in coat, cow, cup, cat) t (as in toe, teeth, top)	Three-quarters of the sounds at two to three years	3 years and up
Can strangers understand his speech?	Yes, from 18 to 24 months	No, two-and-a-half years and up
Language		
Is he putting two words together?	21-24 months	30 months and up
Does he talk in sentences?	Two to three years	Three years and up
Understanding		
Does he usually understand what you say to him?	Yes	No
Does he have to watch you in order to understand?	No	Yes
Responses to Speech (not noise)		
Does he hear you when you call him from a distance of several yards?	Yes	No
When in the same room do you have to raise your voice to get him to hear you?	No	Yes
Hearing Problems		
Do any relatives have hearing problems (other than through aging)?	No	Yes
Does he ever complain of earache?	No	Yes
Do you think he has any difficulty in hearing?	No	Yes

If the child is rated abnormal in speech only, the first area listed above, a hearing loss is not indicated. If the child is rated abnormal in two or more of the other areas, then hearing should be checked.

SOURCE: Ling, op. cit., p. 8.

hard of hearing youth have the greatest need for these services before age 5, and they obviously cannot receive them until the handicap has been identified.

We have already mentioned several options for reaching preschool children, including a "high-risk registry" activated at the time of birth, working through well-baby clinics or nursery schools, and making simple screening tools available to parents for home use. But perhaps the most promising means of identifying preschool hearing or vision handicapped children is a type of "free check-up" system using pediatricians. Simple data/administrative procedures could be developed to aid in this type of identification. For instance, the simple form in Fig. 4.3 is used in Kansas. We would go further and recommend that each child be entitled to "free check-ups" at various times between age 0 and 5, with an age 2 medical check-up to include quality screening for hearing and vision impairment. These checkups could be performed by pediatricians or other service personnel, who could be reimbursed through National Health Insurance or some other program for every child they screen *and* report on to a health or other prescribed government agency. In brief, we recommend that:

- Various options for identification of 2 to 3 year old children for hearing handicaps be thoroughly evaluated with the goal of developing a reproducible model or models for full-scale implementation throughout the country, and then, when viable models are developed that:

Preschool Multiphasic Screening

Name of Child:		Birthdate:		Physician's Name:	
Parent's Name:		Address:		Phone: USD No.	
	Test	Retest	Referral	Remarks	
Denver Developmental Screening Test					
Hearing					
Hemoglobin					
Immunizations—T. B. Skin Test					
Speech					
Physical Inspection					
Urinalysis					
Vision					

KSDH MCH KANSAS STATE DEPARTMENT OF HEALTH Copies: 1 School 3 Local Health Dept.
2 Parents 4 Kans. State Dept. of Health

Fig. 4.3—Kansas form for preschool multiphasic screening

- A comprehensive hearing identification program be instituted throughout the United States designed to reach preschool-age children.

School Hearing Screening

As with vision screening, carefully controlled studies of the reliability of the existing school vision screening tests have not been routinely done on a national scale. It appears that "sweep frequency screening"⁹⁸ is a common method of choice, and is one of the simplest and most reliable methods. Other general findings include the following:

- Good screening depends significantly on the skill of the screener and the quality and calibration of the audiometer employed.
- Follow-up is the critical ingredient in a good as opposed to unsatisfactory hearing conservation program (as was the case with school vision screening).
- Teachers in the early elementary grades, if trained to observe and recognize behavioral clues, are an underutilized source of early identification.

By way of encouraging the thorough evaluation of all existing school hearing screening programs, the following general questions are offered for consideration. These should prove useful for those actually involved and for those interested in the aggregate effectiveness of school hearing screening programs:

- Are true positive identifications routinely and systematically made as confirmed by competent diagnosis?
- Is the screening staff well trained and using technically reliable audiometers?
- Are new students screened?
- Are screenings done several times during the child's school career? (Some hearing disorders are degenerative, and a true negative at school entrance could become a false negative over time.)
- Are records complete and accurate?
- Have diagnostic procedures been reliable, and has follow-up worked satisfactorily?

⁹⁸ A.W.G. Ewing, "Sweep Frequency Method of Making Screening Tests of the Hearing of School Children," *British Medical Journal*, No. 4094, 1955.

- Have services been provided to those in need, such as hearing aids?
- How is the local program generally regarded by specialists in the area?

Our recommendations for school-age hearing handicapped children parallel those for school-age vision handicapped children, and include a comprehensive mass hearing screening program designed to reach every school-age child. This early school-age screening theoretically would be the second for some children, and would be expected to catch handicaps that develop after the first age 2 screening, to catch those less severe hearing handicaps that may have been missed earlier, and to catch those youth who escape the age 2 identification net altogether.

RECOMMENDATIONS FOR IDENTIFICATION PROGRAMS

A number of problems with and concepts for improving the identification service have been discussed in the course of this chapter, and are summarized in the following recommendations.

- Various existing hearing and vision impairment identification programs, for both school-age and preschool-age children, should be thoroughly evaluated to learn details of their operation that contribute to effectiveness, and to assess their costs, benefits, and suitability for implementation throughout the country.
- When that evaluation is complete, a comprehensive mass screening program for aural and visual handicaps should be instituted throughout the country, designed to reach every young school-age child.
- High-risk registries appear desirable, especially for children at risk in the 0 to 5 year age group not normally in contact with public service institutions. Registries should be improved where they exist, and created where they do not. High-risk infants should be screened at birth, one to three times between birth and age 5, and again upon entering school.
- Persons in contact with preschool children, such as parents, day care personnel, nursery school teachers, well-baby clinic personnel, social workers, pediatricians, and nurses, should be sensitized to the possible existence and effects of hearing and vision impairment, and provided with knowledge of relatively simple tests for signs and symptoms of such impairment. Existing institutional settings to catch the missing cohort aged 0 to 5 should be exploited as fully as possible to improve the chances that a child will be identified.
- If detailed evaluation confirms its apparent desirability, each child could be given "free check-ups" at various ages, with an age 2 medical check-up to include quality screening for hearing and vision impairment. Reimbursement to pediatricians or other service personnel could be through National Health Insurance or some other program, and would follow their reporting the screening results to a health agency or other prescribed government agency.
- Follow-up to see that the identified child receives diagnostic and other needed services should be a component of every screening program.
- Efforts should be expended to collect all standards currently in operation for all official hearing and vision screening programs throughout the country. These standards should then be summarized and analyzed with the end in view of

developing a "model" code for hearing and vision screening, including all procedural details required to fully describe the elements in the identification process model.

- State certification and licensing boards are encouraged to consider requiring general, family and pediatric practice physicians to demonstrate proficiency in the various hearing and vision screening and diagnostic procedures. We further encourage such certification and licensing bodies to consider the need for improved and common standards for those paraprofessional and allied-skills professionals who conduct screening and diagnostic procedures, and for test instruments and procedures.
- A program requiring physicians and teachers to report all handicapping conditions to parents, the State Department of Public Health, and the Department of Education should be carefully designed and implemented. We recognize the real possibility that privacy and service desirability norms may clash in this case, but believe that careful design of the procedures insuring legal and moral safeguards is possible and desirable.
- A coordinated and directed national research program should be supported, whose basic purpose is the production (research, testing, and development) of reliable mass screening instruments and procedures. Such work as exists at present is not well coordinated and generally is not directed to the operational aspects of implementation.
- The Regional Direction Centers discussed in Chapter 3 would do much to focus local attention on and coordinate the general identification process, and direction is the next logical step in obtaining services after the child is identified.
- We recommend that a national program be established for the collection, compilation, analysis, and dissemination of data on handicapped children, beginning with the aurally and visually impaired as a "manageable" subset of the total population for purposes of early implementation. There are few national data of comprehensive and reliable quality on handicapped youth, mainly because no one at the national level has this responsibility. Finally, the feasibility of conducting a special census of handicapped children should be considered.

Chapter 5

MEDICAL PROGRAMS AND SERVICES

INTRODUCTION

This chapter considers medical treatment services for hearing and vision handicapped youth, and presents an assessment of federally supported medical programs for all handicapped children.

Medical programs that bestow large benefits on the lives of all handicapped children are summarized as best we can, given the dearth of programmatic information and data on the status and needs of the vision and hearing handicapped subset of the population. While there are three main federally supported medical programs serving handicapped youth—Medicaid, Maternal and Child Health Service, and Crippled Children's Service—many more are to be found in rehabilitation programs, in Department of Defense programs for military dependents, in the Veterans Administration, in OEO, in NIMH, in Project Headstart, and so forth.

A number of program recommendations are developed and related to short-term and longer-term implementation time frames.

In the short term:

- We recommend that the Office of the Secretary of HEW conduct a full-scale evaluation of all programs supported by the Maternal and Child Health Service (MCHS), with the end in view of concentrating future resources on the most critical needs and most effective programs. The remaining programs would be candidates for termination. Research studies on specific disorders should be transferred to the cognizant National Institute of Health.
- Pending resolution of difficulties that have been experienced with the present Medicaid program, and pending the adoption of National Health Insurance or some other program designed to make good-quality comprehensive medical care available to all youth, we recommend that the Crippled Children's Service (CCS) program be retained and expanded.
- Consideration should be given to integrating the CCS and Medicaid programs in the states. The desirable comprehensive and financially open-ended nature of the Medicaid program could benefit from some of the apparently better program administration features of CCS, which also provides medical treatment for handicapped youth in financially needy families. A thorough evaluation of methods and effects of integration should precede implementation.
- Significantly improved management procedures should be implemented to yield much better Medicaid program management information; to cut delays; to improve the equity of eligibility standards; to insure that mandatory provisions are implemented (e.g., screening); and to permit revision of medical payment schedules to reflect the realities of the medical marketplace. Coverage of all Supplementary Security Income recipients should be assured.

In the longer term:

- We endorse the concept of National Health Insurance (NHI), provided that it includes coverage of medical services to *all* handicapped youth in need, and includes provisions (outlined later in this chapter) for meeting the *special* needs of handicapped persons. HEW, in particular the Office of the Secretary or the proposed Office for the Handicapped, might review and react to *all* NHI proposals to assess the likely effects of each on the lives of handicapped persons.
- In related areas, the proposed Office for the Handicapped, could also strengthen and coordinate the "missing" or "underdeveloped" services of prevention, identification, and direction. This would provide needed leadership for three service areas having profound implications for medical and other services but for which no one federal authority presently has assumed prime responsibility.

The chapter then discusses medical treatment services for vision and hearing handicapped children. It summarizes available prevalence data (disaggregated as far as possible according to age and type of affection), characterizes most of the commonly encountered disorders, and briefly describes various treatment methods and costs for each. The section concludes with a series of recommendations related to medical treatment:

- The Department of Health, Education and Welfare (the proposed Office for the Handicapped or the Office of the Assistant Secretary for Planning and Evaluation) should institute a thorough and continuing periodic review of current data-collection and utilization procedures and resources with respect to handicapped children, as a first important step in improving services to the handicapped generally, and with the intent of implementing steps to improve the availability and use of information. The National Eye Institute (NEI), the National Institute of Neurological Diseases and Stroke (NINDS), and The Bureau of the Census, among others, should be consulted with the end in view of preparing a segment of questions on medical and other services to the handicapped population for inclusion in the 1980 Census of the Population. Improved information could do much to inform legislative and executive agency actions that ultimately affect the lives of the handicapped population. Information does not presently exist in the quantity, in the form, or with the reliability necessary to accomplish this critical task.
- Medical fee payment schedules should be revised to reflect the realities of the medical marketplace.
- With an improved research management information system, the proposed Office for the Handicapped or NEI and NINDS could launch catalytic activities to diffuse improved medical treatment methods by identifying promising research findings and then stimulating the development work required to make these research findings of general, practical use. No one at the federal level currently has prime responsibility to insure that research results are developed and disseminated in such a fashion. The result is that the process, if it occurs at all, is protracted unnecessarily. In-service training of specialists who are not at the forefront of medical treatment knowledge is presently no one's prime responsibility.
- Previous recommendations for the direction and identification services should be adopted as expeditiously as possible (see Chapters 3 and 4).

MEDICAL TREATMENT PROGRAMS

Federally supported programs providing health services are estimated to have assisted at least one million handicapped children in FY 1971. (Over one and one-half million were reported to have been served by the different health programs, but some unknown amount of double-counting occurred because of children receiving services from more than one program.) Total federal and state expenditures in this area were at least \$315 million in FY 1971, of which the federal share was \$205 million and the state share was \$110 million. State and local expenditures not known or reported to the federal government would raise the total even further. The largest single federally supported program in this area is Medicaid, which serves youth from financially needy families. It was estimated to have expended some \$186 million in FY 1971 for all handicapped youth. The second largest program is the Crippled Children's Service (CCS), which is designed to serve children having nearly all types of handicapping conditions; it expended at least \$88 million in FY 1971. These and many other federally supported health programs, mainly within the Maternal and Child Health Services (MCHS), are described in Chapter 8 of Rand Report R-1220-HEW. We discuss them here insofar as they relate to aurally and visually handicapped youth.

Programs within the National Institutes of Health are described in Chapter 9 of R-1220-HEW, and are discussed in this report's Chapter 6 on prevention of sensory handicaps in youth. That discussion also is relevant to medical treatment, since NIH activity is aimed both at prevention and at improved medical treatment.

Our best estimate is that, of the \$315 million expended for health services to all handicapped youth in FY 1971, \$28 million was for aurally handicapped youth and \$29 million was for visually handicapped youth.¹

With the exception of the Crippled Children's Service program, there are few reliable program-level data on hearing and vision handicapped youth receiving medical treatment services from federal and state-supported programs. Medicaid, the largest program, simply has not compiled accurate information according to the kind of handicapping conditions presented by its recipients. For CCS, population data are much better but are still not exact because the reporting unit employed is "condition," and one person may possess multiple conditions; furthermore, CCS does not report the extent of handicapping due to the reporting condition, and the cost of providing treatment for that condition. Table 5.1 presents all hearing and vision conditions reported in the 1970 CCS caseload. They are the best data available—and virtually the only reliable data available.

The following discussion approaches the largest government supported health programs from a point of view more general than that of hearing and vision handicapped children alone. It seems reasonable to do so, given the lack of disorder-specific information, and given our belief that any far-reaching improvement made in the existing programs will accrue to sensorially handicapped as well as to all handicapped children. The second half of the chapter deals with specific medical treatment service considerations for the visually and aurally impaired population.

Maternal and Child Health Service (MCHS)

Established in the beginning with amendments to the Social Security Act of 1935, the Maternal and Child Health Service programs have undoubtedly contribut-

¹ Rand Report R-1220-HEW, pp. 164-166.

Table 5.1

CCS CASELOAD OF AURAL AND VISUAL DISORDERS, 1970

Type of Disorder	Percent of Total CCS Caseload	Number of Conditions Treated	Estimated Size of Vision and Hearing Handicapped Population Aged 0-21, 1970
Aural			
Otitis media without mention of mastoiditis	2.7	17,139	
Mastoiditis	0.1	1,005	
Conductive hearing impairment	1.7	11,003	
Sensory-neural hearing impairment	2.0	12,833	
Other central nervous impairment resulting in hearing loss	0.1	791	
All other hearing impairments	1.1	6,835	
All other disorders of the ear and mastoid	0.5	3,331	
Congenital malformation of the ear	0.2	1,698	
Total aural disorders	8.4	51,493	490,000
Visual			
Refractive errors	1.3	8,519	
Strabismus	2.5	15,903	
Blindness	0.1	601	
All other eye disorders	0.8	5,147	
Congenital cataract	0.2	1,425	
Congenital ptosis (eye)	0.1	677	
Total visual disorders	5.0	30,651	193,000
Total aural and visual disorders	13.4	82,144	683,000

SOURCES: U.S. Department of Health, Education and Welfare, *Children Who Received Physician's Services Under the Crippled Children's Program, FY 1970*, MCHS Statistical Series No. 3, December 1971, Tables 14 and 15, abstracted. Population estimates (last column) taken from Rand Report R-1220-HEW, p. 2.

ed to the creation and diffusion of improved health and health practices throughout the country.²

The fundamental concerns of MCHS programs include preventive health services, comprehensive health services for children and pregnant women, child health supervision, identification services, and fostering of good parent-child relations. For instance, some 56 facilities to support the Maternal and Infant Care (M&I) program were funded in FY 1973 at a cost of some \$46.332 million; Intensive Care of Infants was supported at a rate of \$900,000 in some eight separate facilities; and programs for Children and Youth (C&Y) were conducted in 59 facilities at a cost of \$52.842 million in the same period. Each program has its particular objectives. The M&I and C&Y programs were aimed specifically at urban slum areas, for example, and brought medical treatment services to thousands of mothers and children who otherwise would not have gotten them. These programs have had some preventive efficacy, reducing to some extent the number of children who otherwise might have later been "handicapped."

MCHS programs include a variety of activities and services related to the health of handicapped and nonhandicapped preschool and school-age children (e.g., vision and hearing screening, and rubella immunization campaigns). During FY 1972, over 300,000 mothers received maternity nursing services, but no one can say how many

² Rand Report R-1220-HEW, Chapter 8. See also William M. Schmidt, "Public Health: Then and Now," *American Journal of Public Health*, Vol. 63, No. 5, May 1973, pp. 419-427, for a historical overview of child health programs in the United States.

of these women actually bore handicapped offspring, or more difficult yet, how many handicaps in children were prevented as a result of these nursing visits. The Crippled Children's Service program is also part of MCHS; we discuss it separately below.

These comments reflect the institutional situation prior to May 1973, when a major reorganization of HEW programs was reportedly undertaken.³ It is too early to assess the outcomes of the changes.

It is practically impossible to measure and summarize the benefits of MCHS programs in any meaningful fashion because of the diversity of programs within the MCHS's purview, the lack of data, and the scant attention to program evaluation over the years. However, MCHS has been responsible for creating many innovative and genuinely worthwhile demonstration efforts at the state level that have stimulated better care for children.

In terms of the process categories of the policy model developed in our companion report,⁴ it is clear that for MCHS, the estimation, implementation, evaluation, and termination phases have been ill developed or greatly underdeveloped. Official attention has been devoted almost entirely to the initiation and selection phases, where the selection procedures have been reflected in the multitude of incredibly varied and disconnected programs currently operated with MCHS support. The limited available resources have been spread so thin that they lose the potential leverage to mount a concerted effort to solve a manageable subset of maternal and child health problems. For instance, about 334,000 mothers received services under the Maternity Medical Clinic program in 1971, but they accounted for less than 9 percent of all live births in the United States; most states offered expectant parent classes, but only 87,760 parents attended them nationwide in 1970; general pediatric clinics provided services to around 200,000 children in 1970, but this represents only about 0.2 percent of the total population who might have benefited from these services.

- We recommend that the Office of the Secretary conduct a full-scale evaluation of all MCHS-supported programs with an end in view of concentrating future resources on the most critical needs and most effective programs. The remaining programs would be candidates for termination. Research studies on specific disorders should be transferred to the cognizant National Institute of Health.

Crippled Children's Service

CCS provides medical services to handicapped youth in financially needy families, but leaves it to state officials to determine which handicapped persons to serve and to define financial need. The word "crippled" in the program title is a misnomer, since the program services handicapped youth with virtually all types of medical problems.

Large variations exist on a state-by-state basis, as compared with national averages of impairment covered, the extent of multiple handicapping reported, and resources expended per recipient. For example, as contrasted with the national percentage breakdowns for the top three disease classes, Wisconsin reported that 39.6 percent of its caseload was concerned with diseases of the nervous system and sense organs, but the figure for Kansas was only 8.3 percent. Disparities in per-client federal expenditures on a state-by-state basis are also pronounced. These figures

³ Summarized in T. B. Clark, "New Federalism Report: Nixon Seeks to Decentralize Management of Domestic Programs," *National Journal*, April 21, 1973, pp. 580-581.

⁴ Rand Report R-1220-HEW, Chapter 3.

range from a low of \$26.90 in Washington, D.C., to a high of \$249.17 in Ohio; the national average is \$117.76.

CCS is reaching only a fraction of those who might benefit from it; and unlike the Medicaid program, CCS is closed-ended, with a fixed annual budget inadequate to meet the need. Categorical coverage, as determined locally according to available resources and local preferences for certain classes of impairments over others, contributes to inequitable coverage from state to state and within the same state at different phases of the fiscal year.

Since even the earliest days of the CCS program, some state programs have achieved remarkable success in creating and implementing the highest standards of medical care for handicapped children. A number of reasons have been suggested for this:

- Medical and other health specialists have been integral in program administration.
- Standards tend to be maintained through peer group review and state and federal advisory committees composed primarily of medical and health specialists.
- The program is evolutionary and has responded to fundamental changes in the character of the served population.
- As compared with their attitude toward welfare-based Medicaid efforts, physicians appear to favor working with and through the CCS, a primarily medical-based service system.
- Monitoring and evaluation of CCS, in terms of requirements for a minimum comprehensive operational data-collection process, are evident (but not well utilized in terms of rigorous analyses and evaluation follow-through).

Besides direct care, CCS has provided technical support to communities, and programming services (i.e., "direction") and planning for individual handicapped children (even when they received no direct financial support for medical treatment from CCS), and has been directly responsible for some specialized and creative treatment programs. A major weakness here, as with MCHS, has been the lack of any *concerted* federal evaluation of the program's activities over the years that could have spotted likely programs for widespread adoption and ineffective ones for elimination.

As mentioned above, the CCS program is financially closed-ended, and states do what they think best with the limited funds available to them. One option is to concentrate on one or a few extremely high-quality programs for a limited number of handicapped children. This strategy often bears fruit in the innovative, high-quality care for which CCS has been justly applauded. But given a fixed or slow-growing total budget and fast-rising costs, this concentration means that other children are not served at all. On the other hand, a state official may spread his resources over as many children as possible so as to offer services on something like an equitable basis. Dilution of service coverage and quality is the hazard with this option. At some point, it is no longer financially desirable for a physician to accept the CCS payment schedules, which are often lower than prevailing private rates. In several interviews, physicians reported a dangerously thin margin between their merely breaking even on a CCS patient and actually losing money. (We have heard of certain specialized physicians and groups who have declined CCS clients on these grounds alone.)

In short, the CCS program can deliver high-quality services, but is financially unable to meet the total needs of the eligible population.

It is a stated federal goal to make high-quality, comprehensive medical services

available throughout the country. As basic first steps toward that goal, someone has to figure out where the best individual programs are operating, determine what makes them "best," what they cost, and how they work, and then figure out what resources it will take to make the "best" generally available.

Commitment and money have been forthcoming to some extent in provisions encompassing the financially open-ended Medicaid program, which partially duplicates the responsibility of the CCS program to provide medical treatment to financially needy families with handicapped youth.

- Pending resolution of difficulties experienced with the present Medicaid program, and pending the adoption of National Health Insurance or some other program to make high-quality comprehensive medical care available to all youth, we recommend that the CCS program be retained and expanded.

Medicaid

Medicaid reached some 8.3 million youth aged 0 to 21 with medical services in FY 1971 at a total dollar cost of \$5.939 billion. Of this total, our best estimate is that some \$186 million from both federal and state sources was expended for about one million handicapped children in FY 1971. Eligibility for these funds and services is determined according to the family's financial need, in addition to the child's medical needs, and varies considerably across states. Instituted in 1965 as Title XIX of the basic Social Security Act, Medicaid was intended to provide comprehensive services within ten years to all who needed but were unable to pay for them. The federal contribution in Medicaid varies from 50 to 83 percent, based on a state's per capita income. The quality of the various state programs is known to be highly variable, as well as can be determined from the spotty evaluations that have been done.

Available data on the program do not show how many of what kinds and degrees of handicapped children are represented in the total served population. To attain wholly reliable data, given the present reporting system,⁵ would necessitate a case-by-case reconstruction, and even at that, there would still be serious problems because the mandatory screening provisions of the program have not been fully implemented (see Chapter 4 above) and the record may not indicate the presence of a handicap.

While the basic services provided under Medicaid are undoubtedly an improvement over the previous situation, the program's welfare basis and the prevalence of welfare administration have caused other difficulties besides those related to medical data collection, evaluation, and reporting. Some states have shown reluctance to match Title XIX dollars, an understandable eventuality where "welfare" has taken on important negative connotations, particularly at election time. Standards for the health care provided under Medicaid have not been generally established, an omission traceable to the relatively lower participation of health professionals in the state planning and programming processes, as compared with the CCS program. Program emphasis has been on treatment, but since 1967 there have been provisions for mandatory early and periodic screening, diagnosis, and treatment of Medicaid-eligible children. Compliance and full implementation of these provisions have been hard to attain from the states. Data accounting for total numbers of

⁵ A Medicaid Management Information System was in some early implementation stage as of the end of 1973. If properly employed, this might help to sort out some of the persistent and egregious data deficiencies of the current program. Thorough evaluation of MMIS to ease and improve its operation would seem to be in order.

individuals screened, referral rates, disease incidence and follow-up measures undertaken are beginning to be collected, but the results are incomplete. The basic problem in this case is that the states have little incentive to seek out any more children than are already on the rolls and receiving Medicaid assistance. And, as with CCS, the payment schedule reportedly is often significantly lower than private rates; that deterrent, coupled with red tape and slow payments, has reportedly led more than a few physicians to avoid Medicaid patients. Relative to other federally supported health programs, two other features of Medicaid merit careful attention: it is meant to be comprehensive in covering the financially needy population, and it is financially open-ended. Both are necessary preconditions if one is interested in providing a full range of health services to all eligible and needy members of the population.

In the short run, pending the adoption of National Health Insurance or some other program designed to make quality comprehensive medical care available to all youth, we recommend:

- Integration of CCS and Medicaid program operations in the states should be considered. The desirable comprehensive and financially open-ended nature of the Medicaid program could benefit from some of the apparently better program administration features of CCS. A thorough evaluation of methods and effects of integration should precede implementation.
- Significantly improved management procedures should be implemented to yield much better Medicaid program management information; to cut delays; to improve the equity of eligibility standards; to insure that mandatory provisions are implemented (e.g., screening); and to permit revision of medical payment schedules to reflect the realities of the medical marketplace (for example, the schedules would be tied to an escalator provision sensitive to a medical cost-of-living index compiled by the Bureau of Labor Statistics). Coverage for all Supplementary Security Income recipients should be assured (see Chapter 10 below).

The first recommendation above was suggested by our examination of several of the better state health programs for handicapped children, where a common feature was the pooling of resources available from CCS, Medicaid, and other sources. Common disbursement procedures and "coordination" enhanced program performance at the state level, although the current federal arrangement does very little to encourage such activities. Iowa's CCS agency, in response to our survey questionnaire, commented that "Without a Federal coordinating council, it is not easy to create state coordinating councils. The result is that some services are reduplicated and some are not provided." Our recommendation goes well beyond the concept of a simple coordinating council, and gets to the heart of the matter: consolidation and simplification of current programs and competing bureaucracies. Pennsylvania, in their response to our questionnaire, noted that they are trying to rationalize all programs for the handicapped and further recommended "Merger of all Federal funding for medical problems of children into one agency, with sufficient capacity to conduct cost analysis and impact evaluation of programs." At the state level, the Governor of Pennsylvania has moved to create a Commonwealth Child Development Committee to encourage such activities.⁶ And West Virginia's response to our survey sums up the desired objectives of such a move: "There is great need for concentration of effort and cooperation of agencies and programs to con-

⁶ Governor of Pennsylvania, *Executive Directive No. 35*, March 30, 1972.

serve medical manpower, [and for] better utilization of manpower and facilities, resulting in improved services to the handicapped"; the problem is defined as "duplication of effort caused by new [federal] legislation providing funding in various directions."

The proposed Office for the Handicapped could have an important, even paramount, role to play in consolidation and rationalization. In fact, given the longer-term possibilities for broad coverage and support for medical services under National Health Insurance, there is particular need for one agency, such as the proposed Office for the Handicapped, to have overall responsibility for coordinating services to the handicapped during the transition and phase-in period. Oversights, bureaucratic misunderstandings, and consumer fears are bound to occur in sufficient number and with sufficient impact that the need for such a coordination role at the highest possible level of HEW seems justified.

The need for even minimally adequate management information is urgent, and a primary and expanding job for any proposed coordination agency would be aimed in this direction. The simple fact is that no one agency in the federal government knows reliably how many handicapped children there are, what they need, what services are available to provide for those needs, and how effective those services are.

National Health Insurance (NHI)

Pressure appears to be mounting for a national health insurance program. Besides Administration proposals, various plans have been initiated in the Congress.⁷ The government can, in effect, make sure an insurance policy is available to parents so that a handicapped child does not become an economic catastrophe to a parent who wants to provide proper services for him.

Realistic estimation of the costs and effects of the various proposals has only just begun and will likely progress at a brisk rate in the coming months. The selection process leading to a final decision on whether any proposal will be enacted into law will take considerable time, given the incredible variety of interests involved and the large fiscal implications of the proposed concepts. Finally, implementation will certainly not take place overnight. In short, whatever form National Health Insurance takes if and when it becomes law, it will not be an operating program for some time. It would be surprising if it were operational within the next two years. Consequently, the short-term recommendations for improvement of MCHS, CCS, and Medicaid should not be disregarded.

- We endorse the concept of National Health Insurance as a long-term solution, so long as it includes coverage of comprehensive medical services to *all* handicapped youth in need, and provides for the *special* needs of handicapped persons.

In the longer run, NHI could do much to reduce the current reliance of the handicapped on scattered noncomprehensive medical programs that do not serve significant proportions of those in need. The legitimate specialized needs of the handicapped can best be served if NHI includes certain features. For example:

- Any program made into law should explicitly provide for continuity of treatment during the transition from the current to the new system, and should take

⁷ A concise summary of these as of the fall of 1973 is contained in John K. Iglehart, "Health Report: HEW's National Medical Insurance Plan Includes Major Cost-Sharing Requirement," *National Journal Reports*, October 20, 1973, pp. 1570-1571.

into account prevention, screening, extended medical treatment, medically related sensory aids and other equipment, preexisting conditions, extraordinary transportation costs related to medical care, and catastrophic contingencies. Furthermore, those provisions should pertain to all handicapped youth up to age 21 *generally*, not solely to hearing and vision handicapped youth.

The effects of various NHI proposals on the handicapped population deserve special attention from HEW. In particular, the proposed Office for the Handicapped might:

- Review and react to *all* NHI proposals by providing assessments of their likely effects on the lives of the handicapped.

In a related area, that Office might also:

- Strengthen and coordinate the “missing” or “underdeveloped” services of prevention, identification, and direction—in other words, provide needed leadership for three service areas having profound medical and other service and program implications but for which no one federal authority has assumed prime responsibility.⁸

Consider that one Administration proposal for NHI limits preventive care to family planning, maternity, and well-child care.⁹ But a single vaccination program for rubella, even though poorly coordinated and needing some sustaining attention, is saving millions of dollars in continuing medical and other service costs. The costs of vaccination need to be discussed and made explicit. The preventive aspects of the NHI proposals do not appear to have been well enough researched nor their implications well enough considered, especially from the point of view of present and *future* handicapped citizens. (See Chapter 6 below.)

NHI could also provide comprehensive identification of handicaps or disorders leading to handicaps by providing medical screening at age 2, which we recommend in Chapter 4. No one currently has direct responsibility for this needed service and no one is likely to assume it unless directed to do so.

With preschool health screening under NHI, the Regional Direction Centers recommended in Chapter 3 could become a natural access point to the rest of the service system for other nonmedical services, and a ready source of information both for those involved in NHI administration, monitoring, and management and for those receiving NHI whose children are handicapped. The Regional Direction Center would therefore be an “institution in place” to which NHI would naturally and effectively relate.

Another provision of one proposed NHI plan, which calls for an independent and objective assessment of its likely effect, relates to the coverage of eye examinations, eyeglasses, hearing aids, and dental services for children through the age of 12. The selection of the 12-year-old cut-off age appears at first glance to have been made arbitrarily. The realistic and legitimate needs of the young handicapped population aged 13 to 21 are not represented in this provision as formulated. As discussed in Chapter 7, sensory aids are sometimes expensive but generally appear cost-benefi-

⁸ This recommendation attempts to remedy a foreseeable problem that has plagued Medicaid. In stressing medical *treatment*, the program has come under fire for not being concerned about identification and prevention. As Senator Ribicoff is reported to have said, “It’s such a shortsighted policy. A kid who could have had a condition straightened out, and made a functioning member of society, is relegated to spending the rest of his days as a welfare case.” *New York Times*, December 12, 1973.

⁹ As reported in Iglehart, *op. cit.*, p. 1570.

cial; but no current program assures that all children needing aids can receive them. NHI is one clear way to rectify the omission.

The "Government Assurance Program" aspect of one of the Administration's proposals contains several commendable features. One of them is that it provides guarantees, as it were, to those unable to obtain private coverage through the main provisions of the proposal. However, care must be taken that handicapped children with "preexisting conditions" are not denied coverage for medical needs related to the handicap because that condition preexisted the insurance coverage. In a basic sense, handicapped people differ from the actuarial populations used to calculate expected medical payouts in an insurance program, and special consideration must be given to this fact.

Limits on the amount of medical insurance coverage for handicapped youth need to be set with cognizance of possible very high bills for extended medical treatment or potentially very high bills for short-term remedial treatment. Failure to cover expensive medical treatment may cost the system even more in the long run by increasing the costs of other services. Similarly, it could be more expensive for society in the long run if a family failed to obtain medical services because it could not afford the relatively small cost of transportation to a distant special medical facility.

MEDICAL TREATMENT OF HEARING AND VISION DISORDERS

Introduction

The following sections present summaries of common sensory-depriving disorders that are related to handicapping in youth. Taking up vision and hearing disorders in turn, these sections present data on prevalence, descriptions of disorders, common methods of treatment, likelihood of successful treatment, and approximate costs.

Prevalence statistics are not currently available in sufficient detail or comprehensiveness to allow more than the most general assessment of needs in the population based on the etiology or cause of sensory impairment. For etiologies of eye disorders, the NIH-compiled "Model Reporting Area" data are probably the best available in terms of comprehensiveness. However, there are some serious weaknesses with these MRA data: they represent returns from only 16 states; the system is voluntary, with all the problems that entails for timely and reliable information collection; and the data are so gross that meaningful detailed disaggregation according to etiology, degree of handicap, and several other potentially important categories is not possible. Prevalence data on the etiology of hearing disorders are, if anything, even less useful; the national health surveys are prime sources of information, but they are not fully reliable, nor are the data presented in the most useful fashion.

Time-series information of sufficient reliability, coverage, and detail to be useful for policy purposes does not exist. If one conceives of the policymaking process, in one sense at least, as being responsive to changes in the needs and characteristics of a context, e.g., a target population,¹⁰ a politically bounded setting, a problem or

¹⁰ It has been pointed out that fundamental changes occur in the handicapped population, the result in part of improved medical treatment techniques. Ben E. Hoffmeyer, "The Multiple Handicapped Child: A Product of Improved Medical Care," *Medical Times*, August 1951, pp. 807-815.

legislative area, then this absence of any longitudinal information from which timely signals about changes could be determined is acutely distressing.

The descriptive information presented below about vision and hearing disorders was collected and summarized from numerous sources, including medical texts, journal articles, interviews, and conference proceedings. This information is included to give the reader an idea of what the various handicapping disorders are, what causes them, what representative literature exists, and what some of the common methods of treatment involve. Lacking adequate data on prevalence by affection or etiology, we have been only slightly successful in suggesting which among the disorders are relatively more frequent, dangerous, and so forth. General comments about the likelihoods of success for any given treatment of choice are presented, but these assessments will not necessarily pertain in any particular case. Success of treatment varies with the patient's age, state of general health, degree of present impairment, etiology, timeliness and appropriateness of treatment, the skill of those administering the treatment, and a multitude of other factors. In fact, the success rates noted for various treatments are probably biased upward because they have been gleaned from interviews with practitioners in highly specialized, up-to-date, and highly respected practices and institutions. There is no certainty that a general practitioner with little specialized training and fewer specialized resources at his command will attain similar rates of success. Our basic question was of the following form: "If a patient with condition 'x' is treated with the best possible medical care available, what are the odds that the treatment will be successful?"

Widespread realization of these "optimal" success rates appears less related to marginal improvements in technique than to institutional changes that would result in making the appropriately specialized skills available to all of those who need them. Research and hoped-for breakthroughs, as for instance being able to successfully treat most sensorineural deafness,¹¹ will certainly result in spectacular and highly beneficial outcomes—when they occur; however, improvement in reducing the aggregate incidence of disability is currently possible simply by making the known procedures and technical skills more accessible to those in need. Our comments and recommendations regarding the direction and identification services (Chapters 3 and 4) are aimed at this issue.

A major problem with medical treatment for disorders capable of causing sensory handicaps in children is what we have termed the informational services. Treatment procedures exist to correct, stabilize, or alleviate a large number of the primary conditions causing handicapping. But if the child is not identified early enough, properly diagnosed, and then directed to competent medical treatment, the likelihood that a skilled ophthalmologist or otologist will be able to retrieve the situation is *greatly* diminished. Furthermore, the costs for such medical treatment are sometimes absolutely high but usually relatively low as compared with life-time service costs associated with reduced sensory capacity. Magnificent technologies and highly skilled physicians exist, but the institutional mechanisms needed to insure that the children in need get to these services either do not exist, or languish at a stage of inadequate development. *Without adequate identification and direction, the system is simply not achieving its potential.*

Presuming that the child has been identified, properly diagnosed, and well directed, important considerations must still be taken into account before medical treatment begins. No generally applicable comments can be made about these ex-

¹¹ For an up-to-date comment on this, see John R. Lindsay, "Profound Childhood Deafness: Inner Ear Pathology," *The Annals of Otolaryngology, Rhinology, and Laryngology*, Supplement No. 5, Vol. 82, March-April, 1973.

cept to say that each must be seriously considered by the physician, the patient, and the patient's family and that the process is fundamentally unique to each case.

- What are the risks of complication from the proposed treatment? From diagnostic procedures?
- What are the dollar costs of tests and treatments? How much testing is "enough," given resource limitations? Time limitations? Should the patient's ability to pay enter into the medical decision, and if it does, what are the likely consequences for the patient's well-being? For the likelihood of cure? For long-term societal costs?
- What are the patient's general characteristics with respect to age, sex, and general health? How do any of these enter into the assessment of what should be done by way of recommending treatment?
- What are the possibilities for spontaneous change in the patient's condition? What might happen if nothing is done? If some action less than "total" medical intervention is taken? If total intervention is undertaken? Does one adopt a conservative or a more daring approach in the individual case? With what consequences? Who benefits from and who pays for those consequences?
- What are the patient's general feelings about the desirability of likely outcomes? What are the medical feelings? Societal feelings?
- How do considerations of malpractice suits enter into physician's calculations about various courses of treatment? What is the current "going rate" for various procedures and treatments?
- What is the orientation of the institution where the treatment will be administered? Is it a research facility where higher-risk procedures might be adopted? Is it a more conventional setting where "state of the art" talent and supporting resources are not so readily available?

This is a far from complete list, but it does give one a sense that the decision to pursue a course of medical treatment is far from automatic, even presuming that the disorder is well and properly diagnosed. These decisions are made in "real time" by the physician and patient.

Vision Disorders: Prevalence Data

Data on the prevalence of specific eye disorders causing vision impairment are not complete. Some of the most reliable detailed estimates are those reported for the "Model Reporting Area" (MRA) legal blindness prevalence rates. These data are compiled through the voluntary association of 16 states and represent about one-fifth of the total U.S. population.¹² However, these data are of limited value since, as indicated in Appendix A of our Report R-1220-HEW, legally blind youth are only a fraction of the visually handicapped population of concern to this study. Supplementary, but dated, information on age-specific details of the visual impaired population is contained in the National Society for the Prevention of Blindness "Fact Book."¹³

¹² Harold A. Kahn and Helen B. Moorhead, *Statistics on Blindness in the Model Reporting Area, 1969-1970*, National Eye Institute, DHEW Publication No. (NIH) 73-427, Washington, D.C., 1973. States reporting in the MRA included: Connecticut, Georgia, Kansas, Louisiana, Massachusetts, New Hampshire, New Jersey, New Mexico, New York, North Carolina, Oregon, Rhode Island, South Dakota, Utah, Vermont, and Virginia.

¹³ National Society for the Prevention of Blindness, *Estimated Statistics on Blindness and Vision Problems*, NSPB, New York, 1966; world-wide data of even less reliability are reported in Leonard T. Kurland et al., *Epidemiology of Neurologic and Sense Organ Disorders*, Harvard University Press, Cambridge, 1973. Elizabeth Macfarlane Hatfield, "Blindness in Infants and Young Children," *Sight Saving*

In spite of the questionable quality of the data, several gross features of that portion of the legally blind population reported in MRA statistics are worth noting. (See Tables 5.2, 5.3, and 5.4.) First, somewhere between 15 and 20 percent of the total have either "unknown," "undetermined," or "not specified" causes of blindness. Second, prenatal cataracts, retinal disease, and retrolental fibroplasia account for the largest proportions of the reported total. (Each disorder is described in the next subsection.) And third, prenatal influence is far and away the most prevalent etiology class for those age 19 and under, with 57 percent of the total new additions to the registers of legally blind persons. (We caution that legally blind persons are a minority of the visually handicapped population, and other groups of visually handicapped persons will have different prevalences of etiologies.)

This prenatal influence class includes coloboma, absence of part or all of the eye; congenital cataracts; glaucoma; albinism; hereditary retinal degenerations; and other disorders described in the next section. Because little is known about the exact prenatal factors, however, making even informed "guesses" about research priorities is basically impossible.

The need for identification procedures is supported by recognizing how poor are the existing data on causes, and by noting the low *reported* prevalence below age 5

Table 5.2

ESTIMATED PREVALENCE OF LEGAL BLINDNESS BY SITE AND
TYPE OF EYE AFFECTION, U.S., 1960 and 1962

Site and Type of Affection	Number of Persons by Age, 1960			Number of Persons by Age, 1962		
	All Ages	Under Age 5	Ages 5-19	All Ages	Under Age 5	Ages 5-19
Eyeball						
Glaucoma	54,120	140	1,630	56,190	140	1,670
Myopia	20,980	210	1,700	21,770	220	1,740
Other	<u>20,810</u>	<u>520</u>	<u>5,380</u>	<u>21,560</u>	<u>540</u>	<u>5,530</u>
Total eyeball	95,910	870	8,710	99,520	900	8,940
Cornea	18,330	50	600	19,050	50	630
Lens						
Cataract	84,880	400	4,040	88,130	420	4,150
Other	<u>1,630</u>	<u>30</u>	<u>210</u>	<u>1,690</u>	<u>30</u>	<u>220</u>
Total lens	86,510	430	4,250	89,820	450	4,370
Uveal tract	19,120	110	1,670	19,840	110	1,720
Retina						
RLF ^a	12,610	600	11,930	12,710	370	12,060
Other	<u>100,610</u>	<u>250</u>	<u>2,590</u>	<u>104,480</u>	<u>260</u>	<u>2,660</u>
Total retina	113,220	850	14,520	117,190	630	14,720
Optic nerve	40,690	260	3,330	42,240	270	3,430
Vitreous	730	(b)	40	770	(b)	50
Undetermined and not specified	10,490	210	2,300	10,870	220	2,370
Total, all sites	385,000	2,780	35,420	399,300	2,630	36,230

SOURCE: National Society for the Prevention of Blindness, *Estimated Statistics on Blindness and Vision Problems*, NSPB, New York, 1966, p. 52, Table 14.

^aRetrolental fibroplasia.

^bNo data or less than 5.

Table 5.3

AGE-SPECIFIC RATES OF PERSONS ON MRA REGISTERS,
BY CAUSE, 14 STATES, DECEMBER 31, 1970
(Rate per 100,000)

Cause	All Ages	Under Age 5	Ages 5-19
Glaucoma	16.2	0.1	0.2
Myopia	4.3	0.1	2.4
Cornea or sclera	6.9	0.2	0.8
Cataract, total	19.2	1.9	6.4
Prenatal	5.7	1.9	6.0
Other	13.5	0.0	0.4
Uveitis	7.5	0.2	1.3
Retinal disease, total	36.6	1.0	6.0
Prenatal	10.5	0.8	4.2
Diabetic	6.9	0.0	0.0
Other	19.2	0.2	1.7
Retrorenal fibroplasia	3.7	0.9	8.1
Optic nerve	13.5	1.4	5.3
Multiple afflictions	6.4	0.0	0.2
Other	15.9	3.7	12.7
Unknown	16.3	1.1	4.8
Total	146.5	10.5	48.3

SOURCE: Kahn and Moorhead, op. cit., p. 135.

NOTE: Table excludes New York and Massachusetts because of reporting difficulties for age-specific data.

Table 5.4

PERCENTAGE DISTRIBUTION OF FIRST ADDITIONS TO REGISTERS
BY ETIOLOGY CLASS, ACCORDING TO AGE: MRA, 1970

Etiology Class	All Ages	Under Age 5	Ages 5-19
Infectious disease	2.3	12.0	7.1
Injury or poisoning	3.6	8.9	5.1
Neoplasm	1.1	4.7	3.9
Diabetes	12.7	0.0	0.5
Senile degeneration	24.6	0.0	0.0
Vascular disease	2.6	0.0	0.0
Other general disease	1.4	3.6	1.5
Prenatal influence	14.4	56.8	57.4
Multiple etiologies	7.7	0.0	0.8
Unknown to science	12.3	0.0	3.4
Not reported or determined	17.4	14.1	20.4
Total	100.0	100.0	100.0

SOURCE: Kahn and Moorhead, op. cit., p. 75, Table 17d.

compared with ages 5 to 19. We cannot overstress the need to do something about the nonexistent data upon which hundreds of millions of dollars of programs and policies are being "planned" and "evaluated," nor the need to deliver specialized medical treatment services to presently unidentified children under age 5.

Table 5.5 is a breakdown of the legally blind population by degree of reported visual acuity.

Table 5.5

NUMBER OF PERSONS ON MRA REGISTERS BY VISUAL ACUITY
AND AGE, AS OF DECEMBER 31, 1970

Acuity	All Ages	Under Age 5	Ages 5-19
Absolute blindness	10,518	126	1,397
Light perception	11,296	108	1,235
Light projection	1,114	8	103
Less than 5/200	15,891	29	786
5/200 to less than 10/200	9,674	10	576
10/200 to less than 20/200	15,757	19	1,190
20/200	22,449	17	2,399
Restricted field	7,218	0	234
Unknown	5,430	201	1,233
Total	99,347	518	9,153

SOURCE: Kahn and Moorhead, op. cit., p. 113,
Table 27b.

Vision Disorders: Description and Medical Treatment

Some of the more common visual disorders affecting children are briefly sketched out in this section, including a brief discourse on common treatment methods. Also included is a general idea of the likelihoods of outcomes of treatment and attempts at prevention of the disorder. None of what follows is meant to be construed as definitive; on the contrary, our basic purpose is a merely descriptive orientation. The interested reader is strongly encouraged to consult one of the listed general sources for more detailed coverage.¹⁴

Prevalence data on etiology are not sufficiently detailed to give one a very good idea about the relative rates of occurrence and expectations of a handicapping condition resulting from any given disorder, and the ordering of specific disorders in what follows thus does not represent relative prevalence.

Strabismus. Some 5 percent of all children have a deviation in the eyes either inward, outward, or vertically. Strabismus may be observed at or shortly after birth or may develop up to about 3 years of age. The disorder can often be diagnosed by simple inspection or one of several simple tests, e.g., corneal light reflection or the

Review, Vol. 42, No. 2, Summer 1972, pp. 69-89, has produced a detailed study of prevalence data collected on children aged 0 to 6 for the National Society for the Prevention of Blindness in a one-time survey. Hatfield's specific estimates differ somewhat from the MRA data but not sufficiently to change any of the following discussion.

¹⁴ A general, layman's account is contained in Bernard Seeman, *Your Sight: Folklore, Fact, and Common Sense*, Little, Brown, Boston, 1968. Among the large number of more technical treatments we found the following to be of general use: Frank W. Newell, *Ophthalmology: Principles and Concepts*, C. V. Mosby, St. Louis, Missouri, 1969 ed.; and Philip P. Ellis, "Eye," in C. Henry Kempe et al., *Current Pediatric Diagnosis and Treatment*, Lange Medical Publications, Los Altos, Calif., 1972 ed., pp. 197-213.

cover test. Such tests are important because a child may have strabismus that is not readily observable. Early treatment of strabismus is important because, uncorrected, it may lead to inadequate development of central vision. (See below, amblyopia ex anopsia). The importance of preschool identification screening of children must be stressed because treatment tends to be more effective, and the prevention of lost vision through amblyopia greater, the earlier the disorder is identified, diagnosed, and treated.

Exercises, corrective lenses, and/or "patching" the good eye to force development of macular vision in the underdeveloped eye are all treatments encountered.¹⁵ In addition, surgical intervention to correct the deviation may be necessary, and has a greater likelihood of effecting a functional cure if it occurs early in life rather than being delayed until the child reaches 4 or 5 years of age.

Strabismic or suppression amblyopia. This term, meaning weak or dull vision, describes a disorder in which the affected eye is not providing adequate sensory information, even though there usually is no medically observable damage to the eye. Loss of vision from disuse, strabismic or suppression amblyopia (amblyopia ex anopsia), is a specific form of the disorder that is prevalent in children. Other forms exist, e.g., those caused by toxic substances, diabetes, complications of diphtheria, and hysterical disorders. Early identification and correction of the ex anopsia form are critical in a sight conservation program; hysterical causes are sometimes dealt with successfully by specialized psychological or psychiatric means; and a variety of medications exist to treat the toxic forms. Patching of the good eye for periods of as great as three months is used to encourage proper fixation. If patching is not sufficient, pleoptics is a method of choice of some physicians for additional treatment.¹⁶ If the cause is strabismus, the treatment is as for that disorder.¹⁷

Retrolental fibroplasia (RLF). Essentially, RLF is due to excessively high oxygen concentrations or levels in the blood of premature or respiratorially distressed infants. First occurrences of the condition were noted in the 1940s, and in the mid-1950s it was listed "as the chief cause of blindness in infants."¹⁸ While the mechanisms responsible for the disorder (development of a fibrous mass leading to a possible detachment of the premature infant's retina) are not completely known, it is known that excessive oxygen is the precipitating agent. In the premature or otherwise respiratorially distressed infant, high concentrations of oxygen may be required for several days after birth. Excessively high concentrations in the infant's blood cause the RLF. The role of the ophthalmologist is important in conducting oxygen therapy in infants. Frequent tests of the arterial blood oxygen content should be made to determine whether the levels of oxygen received are excessive and may cause damage to the retinal vessels. Periodic ophthalmoscopic examinations may

¹⁵ Gunter K. Von Noorden, "Strabismus: Annual Review," *Archives of Ophthalmology*, Vol. 84, 1970, pp. 103-122; and Gunter K. Von Noorden and A. E. Maumenee, *Atlas of Strabismus*, C. V. Mosby, St. Louis, Missouri, 1967.

¹⁶ Pleoptics is a relatively new orthoptic technique in which the eye is stimulated with a bright light, causing a circular after-image (as when one fixes on a bright light and then "sees" a colored circle when the eyes are closed). The eye is then made to fix on smaller and smaller targets until fixation is improved. It is expensive because equipment is expensive and a course of treatment may be prolonged and of high frequency.

¹⁷ Von Noorden, op. cit.

¹⁸ F. H. Adler, *Gifford's Textbook of Ophthalmology*, 6th ed., Saunders, Philadelphia, 1957, p. 358. See also, A. Patz, "A New Role of the Ophthalmologist in Prevention of Retrolental Fibroplasia," *Archives of Ophthalmology*, Vol. 78, 1967, p. 565.

also be conducted, although assessment of damage to the retinal vessels may be difficult.¹⁹

It is distressing that, some 20 years after its causative mechanisms were identified, this essentially preventable disease is still showing up in recently published Model Reporting Area data for those under the age of 5 years (at a rate of 0.9 per 100,000). The rate for ages 5 to 19 is 8.1 per 100,000.²⁰ In interviews it was suggested that in the obstetrician's understandable desire to save the life of a distressed newborn, or in the case of oxygen therapy's being administered more generally throughout the newborn population, some RLF is being caused that could be averted if an ophthalmologist were consulted or if the doctor in attendance were fully aware of the possible damage that otherwise life-saving therapy was doing to his patient's vision.

Nystagmus. Nystagmus refers to the rhythmical movement of one or both eyes. It is involuntary and ranges in severity from slight, hard-to-observe, and nonhandicapping to rapid, readily detectable, and debilitating. Basically, nystagmus results because the eye is unable to fix or focus. Nystagmus occurs in a variety of forms; it is usually congenital in youth. Congenital ocular nystagmus due to sensory defects can be caused by any eye disorder inhibiting fixation in an infant, e.g., scarred cornea, damage to the macula, cataract, and as a result of albinism.

Congenital ocular nystagmus due to defects in the neurological mechanism for fixation is also found in youth. A third entity, called Spasmus Nutans, exists; beginning at a few months of age, a child may develop nystagmus of the eyes which persists up to an age of perhaps 1 or 2 years. There is no known cure for nystagmus, and treatment is seldom effective.²¹ In addition to the above types, nystagmus can be due to a serious central nervous system disorder such as a brain tumor, and this cause should be differentiated.

Myopia. Myopia is a common disorder, familiarly referred to as "nearsightedness." Myopia is a relative imbalance between the refractive power of the eye's cornea and lens and the length of the eyeball, such that light rays do not focus on the macula but form an image somewhere in front of it, with the result that objects at a distance are blurred, and the blurring increases with distance.

Myopia can be hereditarily caused, it can occur because of damage to the cornea, such as by abcess or injury, or it can result from defects of the eyeball, such as an abnormally curved cornea, an abnormally round lens, or an abnormally long globe. Generally, when one eye is myopic, the other becomes so in time.

In something over 90 percent of the cases, myopia is moderate and is self-limiting by the age of about 20 or 21. It is the other 10 percent that concerns us as a cause of handicapping in children. Complicated or progressive myopia, the more severe form of the disorder, has been known in extreme instances to contribute to the tearing and detachment of the retina and to degeneration of the macula—events leading to blindness if not treated correctly and early.

There is no known cure or preventive method for myopia. The need for early and correct identification and diagnosis to improve vision and identify progressive myopia is clear. In more severe instances, even glasses may be inadequate.²²

Astigmatism. Astigmatism can be caused when the cornea, the front or "win-

¹⁹ Frank W. Newell, *Ophthalmology: Principles and Practices*, C. V. Mosby, St. Louis, Missouri, 1969 ed., p. 258. This work has a very thorough section on RLF, its treatment, and methods to be used in the premature nursery. See also J. D. Baum and J. P. Tizard, "Retrolental Fibroplasia: Management of Oxygen Therapy," *British Medical Bulletin*, Vol. 26, 1970, pp. 171-174.

²⁰ Kahn and Moorhead, op. cit., p. 135.

²¹ Newell, op. cit., pp. 423-425.

²² A. E. Sloane, *Manual of Refraction*, Little, Brown, Boston, 1970 ed.

dow" part of the eye, is not perfectly rounded, or can also be caused by irregularity of the lens. These irregularities cause an improper focusing of light rays at a series of points rather than at a single point as in a normal or a myopic eye. In mild forms, the afflicted person may be unaware of astigmatism; in more severe forms it may be handicapping. Astigmatism can be corrected by spectacles in most cases. *Irregular astigmatism* occurs when the cornea is irregular and misshapened, usually because of trauma, ulcers, injuries, disease, etc., to the cornea itself and due to keratoconus. Irregular astigmatism usually cannot be corrected by spectacles, but contact lenses can in some cases overcome the visual disability. In some advanced and severe cases contact lenses may not be sufficient and corneal transplants may be necessary.²³

Cataract. Cataract is a cloudiness of the lens preventing the passage of light to some extent and hence inhibiting vision. Cataract has many causative agents. Among them are general diseases such as diabetes, galactosemia, hypoparathyroidism, hyperparathyroidism, and rubella. In addition, injuries from direct trauma or from radiation can cause cataracts, as can long-term steroid therapy.

Depending on the size and type of cataract, vision is impaired to a variable degree. Impairment may be slight or so great as to only allow perception of light.

No known medication will "cure" cataracts, even though a great deal of research energy has been expended to find something that might dissolve, absorb, retard, or prevent their formation and development. Surgery is the method of choice to relieve the disorder and has been known and effectively used since ancient times in the older person. The treatment of congenital cataracts depends to a large degree on reasonable expectation for improvement for vision. In many cases, cataracts present since birth result in an irreversible loss of vision (amblyopia ex anopsia) which cannot be overcome by surgery. Removal of a cataract extremely early in life may result in improved vision; in many cases removal of congenital cataracts later in life is not effective in improving vision because of irreversible amblyopia ex anopsia.

Cataract is preventable to some extent. Because rubella has been clearly implicated as a causative agent, pregnant women should avoid exposure to the disease, or better yet should be vaccinated against it before becoming pregnant. Trauma and radiation-caused cataract can be prevented by simple avoidance tactics.²⁴

Toxoplasmosis. Caused by a microscopic parasite, toxoplasmosis exists in both congenital and acquired forms. In the congenital form, a variety of presenting symptoms has been demonstrated, e.g., skin rash, jaundice, central nervous system disorder, hydrocephalus, mental retardation. The acquired form may occur at any age and, as with the congenital form, choroid and retinal involvement is known. Accurate diagnosis is hard to attain because the symptoms resemble those of a number of quite different disorders. Treatment involves careful administration of one of a number of sulfa drugs and corticosteroids to reduce and eliminate lesions to the eye. Drug therapy is complex and great care must be exercised. While research into the disorder has been vigorous, preventive measures are not generally agreed upon. It is suspected that pregnant women should avoid all contact with cat feces, as that method of transmission of the congenital form of toxoplasmosis has been identified.²⁵

²³ Ibid.

²⁴ Gunter Von Noorden, S. J. Ryan, and A. E. Maumenee, "Management of Congenital Cataracts," *Transactions of the American Academy of Ophthalmology*, Vol. 74, 1970, pp. 352-359; and Ellis, op. cit., p. 205.

²⁵ H. A. Feldman, "Toxoplasmosis," *Pediatrics*, Vol. 22, 1958, pp. 559-574; A. E. Maumenee (ed.), *Symposium: Toxoplasmosis, with Special Reference to Uveitis*, Williams and Wilkins, Baltimore, 1962; M. J. Hogan, S. J. Kimura, and G. R. O'Conner, "Ocular Toxoplasmosis," *Archives of Ophthalmology*, Vol. 72, 1964, pp. 592-600; and Newall, op. cit., pp. 376-377.

Coloboma. During the first trimester of pregnancy, the development of the eye is most critical. Occasionally, a portion of the eye does not form and what results is a coloboma, a missing part of the eye's structure. Depending upon the severity of the coloboma, the choroid, part of the retina, and/or the optic disc can all be involved. Most commonly, the coloboma results in an absence of part of the iris. If the coloboma affects large or central parts of the choroid and retina or optic nerve, vision may be greatly impaired and by and large treatment cannot be effective.

Aniridia. Aniridia is a developmental defect in which all or part of the iris is absent. As with other developmental problems, there is some reason to suspect hereditary factors and there is usually some additional complicating factor contributing to visual impairment. Cataract, glaucoma, and other disorders often accompany aniridia, and the disorder is unfortunately usually binocular.

Albinism. In cases of albinism where there is no pigment in the eye (albinism may affect only the eye or may be more generally distributed over the body), visual problems almost always will follow. Besides acute sensitivity to light, those affected with albinism usually have some degree of nystagmus and often are myopic as well. Albinism is a genetically related disorder; about one in three cases result from consanguineous reproduction, e.g., children produced by brothers and sisters or close cousins, and others are the result of spontaneous mutation. Procreation by two albinos always results in albinistic offspring. No one knows how to cure or correct albinism, and for the visual component of it, all that can be done is to correct the visual deficit with spectacles and to protect the eye from damage by blocking the sun's rays with appropriately tinted lenses.

Macular degeneration. A number of hereditary conditions impair vision as a result of abnormal changes in the macula, the center of the retina and the location of one's best vision. There are a number of hereditary diseases that result in degeneration of the macula. Usually, macular degeneration is seen in the older person; when it occurs in the younger person, it is usually a hereditary form, and by and large there is no effective treatment for them. Reduction of color vision capability is one of the earlier signs, and this is in time followed by loss of central vision and a general diminution of the imaging capacity.

Retinitis pigmentosa. Resulting in, among other things, defective night vision, retinitis pigmentosa is mainly diagnosed in children over the age of 14, and the disorder progresses through adulthood until a greatly reduced or a total loss of vision occurs. It is binocular and is thought to result from the primary degeneration of the pigment layer of the retina. It is incurable and not preventable, and there is a distinct hereditary tendency.

Retinoblastoma. Retinoblastoma is a relatively rare malignant growth of children. It is sometimes traceable to a family history of the disorder. The disease can become apparent from birth through several years of age. Involvement of both eyes may not be simultaneous, and only about 25 percent of the cases are bilateral. One sign of the disorder is the so-called "cat's eye" or white or yellow reflex in the pupil of the eye due to detachment of the retina or the presence of a large tumor. Early detection of a retinoblastoma is critical as the disease is capable of progressing along the optic nerve and into the brain, out of the eye into the orbit, or via the blood to other bodily organs, with a high likelihood of fatality. Treatment, in any case a truly life-saving operation, involves the removal of the affected eye with special care taken to insure that the tumor has not spread as far as the optic nerve. In the unilateral case, attention is then given to the second eye to detect the earliest signs of the disease. In the bilateral case, the better eye is salvaged, if possible, and x-ray and chemotherapy are undertaken. Parents having survived retinoblastomas should be advised concerning procreation as the odds are significantly greater that

they will produce similarly affected children: if one parent has survived a retinoblastoma, it is about a 50-50 chance that a child will be afflicted. If one child has a unilateral retinoblastoma and there is also a family history of that disorder, chances are about 40 percent that the next child will also be afflicted; with no prior family history the chances the next child will also be afflicted drop to about 4 percent. In the unilateral case, spontaneous or somatic mutation is the more common cause, and accounts for 80 to 90 percent of all cases; the family form accounts for only about five percent of all the cases.²⁶

Hypermetropia. Farsightedness or hypermetropia is a disorder of the eye in which light rays striking the eye would be in focus at a point behind the retina. This disorder can be adequately treated with spectacles. If uncorrected the condition could lead to strabismus.

Dislocated lenses. Either because of developmental problems, metabolic disease such as cystinosis, or because of trauma, usually a sharp blow to the head, the lens may become completely or partially displaced. If only partially, the lens is referred to as subluxated. In the congenital or developmental case, the disorder is often associated with defective formation of the ligaments supporting the lens, has been traced to genetic origins, and is often found in conjunction with other deformities in the body, such as excessively long bones. Complications of dislocation include glaucoma, cataract, and uveitis.

Glaucoma. Basically, glaucoma is a disorder of the eye in which pressure within the eye is excessively high. This condition may lead to damage to the optic nerve, which can be permanent and lead to total blindness. In glaucoma, the normal drainage of fluid produced within the eye is obstructed to some degree, either because of a developmental congenital disorder (some authorities believe it to be a membrane growing over the normal drainage system), because of uveitis resulting in clogging or damage to the drainage system, or because of adherence of the iris to cover the drainage system, which can be secondary to developmental abnormalities in which the lens adheres to the cornea or iris or secondary to a dislocation of the lens. *Primary glaucoma* is a glaucoma which is not associated with an identifiable pre-existing disorder. *Secondary glaucoma* refers to a glaucoma which is due to some other pre-existent disorder such as uveitis, a dislocated lens, or trauma. Blunt trauma to the eye can result in glaucoma which is insidious and may take several months or perhaps years to develop.

Glaucoma demands early, accurate, and complex treatment by an ophthalmologist. The congenital glaucoma is usually treated surgically. That and other forms may also be treated topically with eye drops, systemically with a variety of medications, and surgically by a number of procedures, all of which are meant to reduce pressure within the eye.²⁷

Optic atrophy. Many threats to the optic nerve, the main pathway of visual images to the brain, exist: glaucoma, tumors of the eye and brain, trauma associated with skull fractures, circulatory disorders, infections of the eye or brain, complications of diabetes, anemia, or toxic poisoning, and unknown congenital causes. There is no known means to restore the optic nerve once it has atrophied. Because it is a debilitating complication of several other ocular disorders, research, prevention, and treatment of those primary causes all contribute to the lessening of blindness from this cause.

²⁶ Sir Stewart Duke-Elder, *System of Ophthalmology: Diseases of the Retina*, Vol. 10, C. V. Mosby, St. Louis, Missouri, 1967. See also, W. A. Bedford, C. Bedotto, and P. A. MacFaul, "Retinoblastoma: A Study of 139 Cases," *British Journal of Ophthalmology*, Vol. 55, 1971, pp. 19-27.

²⁷ B. Becker and R. N. Shaffer, *Diagnosis and Therapy of Glaucoma*, C. V. Mosby, St. Louis, Missouri, 1965 ed.

Corneal ulcers and scars. The number of possible causative agents is large and includes, for example, viral infection, trauma, chemical agents, gross vitamin A deficiency, bacterial agents, and so forth. Symptoms include pain, an unusual sensitivity to light, overproduction of tears, and the reduction of vision. Treatment for residual visual impairment may be carried out after the eye has been made healthy and includes corneal transplantation and contact lenses.

Keratitis. An inflammation of the cornea, keratitis is divisible into three basic types: *interstitial keratitis*, usually syphilitic in origin, involving the intermediate layers of the cornea; *deep keratitis*, caused by trauma or infectious agents such as mumps; and *superficial punctate keratitis*, thought to be mainly infectious in origin, and usually treatable. The basic threat posed by the disorder is the scarring it leaves in its wake, with resultant loss of visual acuity.

Burns. Eyelid burns are treated like burns elsewhere in the body, with special care to prevent infection of the eye and deep lid scarring. Preventive antibiotic and corticosteroid therapy may be indicated to reduce chances of infection and to reduce inflammation; such therapy is usually topical, as is therapy designed to minimize corneal scarring. Chemical burns of the cornea require prompt and copious irrigation and subsequent evaluation of the extent of damage and needed medical treatment. Ultraviolet burns of the cornea, e.g., from sunlamp exposure or skiing in bright light without tinted lens protection, may require antibiotic therapy and patching of the eye to reduce chances of infection and discomfort.²⁸

Fracture of the orbit. Usually a traumatic shock to the head or a fist to the eye is responsible for fracture of the orbit. This is a serious disorder that can have a number of complications, e.g., double vision. Significant displacement of the bone surrounding the eye ball requires prompt and skillful surgical intervention. Depending on the severity of the fracture, sight may be impaired.²⁹

Contusions of the globe (including hyphema). Blood in the anterior chamber of eye—hyphema—and an assortment of other sight-threatening results, are known to occur as a result of trauma in and around the eye. Care depends upon the nature and severity of the contusion and the extent of complications resulting from it, e.g., hyphema, retinal detachment, vitreous hemorrhage, glaucoma, rupture of the eyeball, and complications that can occur well after the initiating trauma.³⁰

Foreign bodies. Depending upon the nature of the body and the extent of eye injury it causes, a foreign object in the eye can be sight-threatening. Many foreign bodies in the cornea can be removed simply with a moist, sterile cotton applicator; others may require minor surgical treatment with prophylactic antibiotic therapy; intraocular foreign bodies necessitate more involved procedures with a poor prognosis for visual function.³¹

Retinopathy. Hemorrhages or changes in the blood vessels nourishing the eye are common signs of retinitis; blank, diminished, or distorted vision, as well as sensitivity to light, are symptoms. Retinitis has many suspected causes, including diabetes, high blood pressure, rheumatism, burns from the sun's rays, leukemia, and kidney disease. Infectious causes include untreated corneal or scleral disorders. Parasites, chemicals, and allergic materials have also been implicated in retinopa-

²⁸ R. R. Tenzel, "Trauma and Burns," *International Ophthalmological Clinic*, Vol. 10, 1970, pp. 55-69.

²⁹ B. Becker and T. K. Lyle (eds.), *Fractures of the Orbit*, Williams and Wilkins, Baltimore, Maryland, 1970; and H. B. Stallard, *Eye Surgery*, Williams and Wilkins, Baltimore, Maryland, 1965 ed.

³⁰ Duke-Elder, "Mechanical Injuries," *op. cit.*, Vol. XIV, Part I, 1972; and A. Callahan, *Surgery of the Eye: Injuries*, Charles C. Thomas, Springfield, Ill., 1950.

³¹ D. Paton and M. F. Goldberg, *Injuries to the Eye, Lids, and the Orbit*, W. B. Saunders, Philadelphia, 1968.

thy. The problem is not so much with the disorder itself, but with the damage left in its wake, especially if undetected and untreated.

Uveitis. Diseases of the iris (iritis), ciliary body (cyclitis), and the choroid (choroiditis) can cause handicapping conditions. Although specific causes such as viral infections, injury, or systemic illnesses can cause uveitis, the bulk of the cases of uveitis are due to unknown etiology. While the disorders in general are treatable, their possible complications warrant special consideration, e.g., glaucoma and cataract.³²

Medical Treatment Costs of Vision Disorders

Table 5.6 presents a sample of treatment costs for medical services available to those suffering from vision disorders. These data are a sample of current charges for high-quality care in a specialized practice, and may vary considerably for different parts of the country and for different practices. These estimates are for professional medical specialist fees only; payments for other aspects of medical care, such as days of hospitalization, are excluded.

Two features stand out from this summary sample of treatment costs. First, good-quality medical care can be had, but it can also be costly in the absolute sense. However, the appropriate trade-off is between the cost of such care and all costs involved in a lifetime of being handicapped or more severely handicapped than one would be if good medical care were received. In this sense, good-quality medical treatment is probably a "bargain." Second, the finest specialized medical care in the world is relatively useless, irrespective of its costs, if there are inadequate identification and diagnosis services in operation locally.

Hearing Disorders: Prevalence Data

Data on the prevalence of hearing impairment, but not the causes, are described in Appendix A of Rand Report R-1220-HEW. Data on the causes of hearing impairment in the young are neither comprehensive nor reliable. Data are better for visual disorders. For example, Model Reporting Area data exist on prevalence with respect to site and type of affection for youth aged 0 to 5 and 5 to 19 years, and on age-specific prevalence numbers and rates with respect to cause. Comparable data do not exist for hearing disorders, although a few special studies shed some light on these matters. Some of the best, but limited, available etiological information is contained in the national health surveys. Those data are in many cases over 10 years old, however, and are limited by many sampling and technical problems; but the information in Table 5.7 does show that illness, and congenital causes generally, are the most prevalent for youth under the age of 6. The utility of these data is compromised by the fact that over one-third of the youth surveyed had "unknown" or "other" etiologies, or simply did not respond to the survey questionnaire.

Data on the medical aspects of hearing impairment available through federal surveys have many specific limitations. For example, the national health interview survey data³³ are self-reported by survey respondents without reference to detailed

³² T. F. Schlaegel, *Essentials of Uveitis*, Little, Brown, Boston, 1969.

³³ See, for example, "Current Estimates from the Health Interview Survey, United States—1968," *Vital and Health Statistics*, Series 10, No. 60, Public Health Service, Washington, D.C., June 1970; and Augustine Gentile, Jerome D. Schein, and Kenneth Haase, "Characteristics of Persons with Impaired Hearing, United States, July 1962-June 1963," *Vital and Health Statistics*, Series 10, No. 35, Public Health Service, Washington, D.C., April 1967; and "Prevalence of Selected Impairments, United States, July 1963-June 1965," *Vital and Health Statistics*, Series 10, No. 48, Public Health Service, Washington, D.C., November 1968.

Table 5.6

SAMPLE TREATMENT COSTS FOR VISION DISORDERS IN CHILDREN, SPECIALIZED PRACTICE, CALENDAR YEAR 1973

Item	Charge (\$)	Item	Charge (\$)
Service group/routine/MDs		Surgical procedures	
Office visit	12	Enucleation of eye, without implant	400 ^d
Initial comprehensive diagnostic ophthalmic examination	30	Enucleation of eye, with implant	450 ^d
Initial hospital consultation	35	Evisceration of eye	400 ^d
Routine hospital visit	20	Suture of eye for wound or injury	(c)
Diagnostic group/X-ray		Removal of embedded foreign body	15 ^e
Eye, for foreign body	40	Removal of embedded foreign body under slit lamp	20 ^e
Eye, for localization of foreign body	60	Keratectomy, lamellar, partial	300 ^e
Facial bones, limited	30	Keratectomy, lamellar, complete	350 ^e
Facial bones, complete and/or orbits	50	Pterygium, simple	200 ^e
Facial bones, complete with nasal bones	60	Pterygium, complicated	(c)
Nasal bones	28	Curettage and cauterization of corneal ulcer	40 ^e
Nasolacrimal duct	50	Corneal transplant, lamellar	700 ^d
Optic foramina	30	Corneal transplant, penetrating	800 ^d
Skull, limited	25	Aspiration of aqueous, diagnostic	30
Skull, complete	35	Aspiration of vitreal prolapse	200 ^d
Tumor localization, ocular	70	Goniotomy	250
Diagnostic group/laboratory		Paracentesis	30
Blood count, complete	5	Removal of intraocular foreign body, anterior chamber	400 ^d
Culture sensitivity	10	Severing corneal-vitreous adhesions	(c)
Hydroxycorticosteroid	25	Air injection into anterior chamber	30
Culture	10	Sclerotomy, posterior, with removal of intraocular foreign body by magnetic extraction	400 ^f
Diagnostic/optometry/ophthalmic		Sclerotomy, posterior, with removal of intraocular foreign body by nonmagnetic extraction	450 ^f
Eye examination, including visual acuity, ophthalmoscopy, tonometry, gross visual fields, muscle balance, and slit lamp microscopy	35	Sclerotomy, posterior, with or without drainage of fluid	250
Eye examination, as above, with refraction	45	Sclerotomy for glaucoma, with scissors, punch, trephine, or cautery	350 ^f
Eye examination, as above, with plotting of central and/or visual fields	50	Scleral resection, any type, with graft	700 ^d
Gonioscopy	20	Iridotomy	140
Gonioscopy, infant	60 ^a	Iridotomy, with transfixation of iris	150
Gross external examination with ophthalmoscopy and refraction	30	Iridotomy, photocoagulation or laser	200 ^f
Gross external examination, as above, with cyclopegic of mydriatic	40	Excision of lesion of iris	400 ^f
Orthoptic and/or pleoptic evaluation	25	Iridocyclectomy	600 ^f
Orthoptic and/or pleoptic training (30 min)	15	Iridectomy, any type	300 ^f
Visual fields: plotting, central and/or peripheral	20	Iridenclisis	350 ^f
Tonometry	15	Iridodialysis	300 ^f
Tonography	30	Cyclodiathermy, initial	250
Provocative test(s) for glaucoma, including water drinking, and/or mydriatic, and/or dark room test	20	Cyclodiathermy, subsequent	120
Ophthalmoscopy (fundoscopy) with mydriasis, direct and/or indirect methods	20	Cyclocryotherapy, initial	180
Ophthalmoscopy, as above, with general anaesthetic	40	Cyclocryotherapy, subsequent	90 ^f
Ophthalmoscopy, as above, with contact lens	30	Cyclodialysis, initial	350 ^f
Ophthalmoscopy, as above, with intravenous (fluorescein)	50	Cyclodialysis, subsequent	180 ^f
Ophthalmoscopy, as above, with ophthalmodynamometry	40	Discission, initial	150 ^f
Fitting and evaluation of contact lens	(b)	Discission, subsequent	70 ^f
Miscellaneous and office procedures		Discission, secondary membrane, simple	150 ^f
Injection	5	Discission, secondary membrane, complicated	250 ^f
Medication	(c)	Aspiration of lens material for cataract, one or more stages	500
Surgical nurse	50 ^c	Extraction of lens, unilateral, one or more stages (e.g., cataract, subluxated lens)	700 ^d
Special reports	(c)	Discission of anterior hyaloid (e.g., pupillary block)	150 ^f

^aIncludes 7 days follow-up.^bFee varies (\$250 minimum).^cFee varies.^dPlus 4 postoperative office visits per year for 3 years = \$144.^eMinimum fee.^fPlus 6 postoperative office visits = \$72.^gPlus 9 postoperative office visits = \$108.

Table 5.6--continued

Item	Charge (\$)	Item	Charge (\$)
Reattach retina, retinopexy, with or without drainage of subretinal fluid, initial	600 ^{d,e}	Blepharotomy with drainage of abscess of meibomian glands or styne	20 ^e
Reattach retina, retinopexy, with or without drainage of fluid, subsequent	(c)	Excision of meibomian gland (chalazion), single	40
Reattachment with scleral buckling, resection, implant, initial	900 ^e	Excision of meibomian gland (chalazion), multiple, same lid	40
Reattachment, as above, subsequent	(c)	Excision of meibomian gland (chalazion), multiple, different lids	50
Repair of retinal breaks or schisis, one or more stages during same period of hospitalization, photocoagulation and/or cryotherapy	300 ^e	Conjunctive, removal of foreign body, surface	20 ^e
Photocoagulation, initial	300	Conjunctive, removal of embedded foreign body	20 ^e
Photocoagulation, subsequent	150	Conjunctiva, evacuation of cysts	20 ^e
Diathermy or cryotherapy	(c)	Biopsy of conjunctive	25
Muscle surgery, initial	450	Excision of lesion of conjunctiva, benign	30 ^e
Muscle surgery, subsequent	(c)	Excision of lesion of conjunctiva, malignant	(c)
Muscle transplant	500	Suture of conjunctiva	30 ^e
Orbitotomy with exploration	350	Conjunctivoplasty, free graft using conjunctiva	350
Orbitotomy with drainage of intra-orbital abscess	350	Conjunctivoplasty, free graft using buccal mucous membrane	400
Orbitotomy with removal or intra-orbital tumor or foreign body	(c)	Conjunctival flap for corneal ulcer	150
Excision of lesion of orbit, requiring bone flap	650	Drainage of lacrimal gland, abscess or cyst	120
Orbital decompression	600	Drainage of lacrimal sac: dacryocystotomy or dacryocystostomy	60 ^f
Extenteration of orbit, without skin graft	600 ^g	Excision of lacrimal gland	350 ^f
Extenteration of orbit, without skin graft, including orbital bone	(c)	Excision of lacrimal sac	350 ^f
Retrobulbar injection	20 ^e	Dacryocystorhinostomy	400 ^g
Retrobulbar injection, alcohol injection	60	Conjunctivocystorhinostomy	450 ^d
Retrobulbar injection, air or opaque contrast medium for radiography	30	Closure of punctum by cautery	25
		Dilation of punctum	20 ^e
		Probing of nasolacrimal duct	20 ^e
		Probing and/or irrigation of canaliculus	20 ^e

^aIncludes 7 days follow-up.

^bFee varies (\$250 minimum).

^cFee varies.

^dPlus 4 postoperative office visits per year for 3 years = \$144.

^eMinimum fee.

^fPlus 6 postoperative office visits = \$72.

^gPlus 9 postoperative office visits = \$108.

medical diagnosis; are summarized in too gross a detail ("Diseases of ear" are reported as a summary category including seven international classification code numbers); are categorized by too gross a set of age categories (e.g., "under 45 years"); exclude institutionalized hearing impaired persons; and are often over 10 years old. The national Health Examination Survey³⁴ involved professional reporting, but only very limited information on etiologies was collected, institutionalized persons were not included, and published reports provide only very gross categorical breakdowns.

³⁴ See, for example, "Hearing Sensitivity and Related Findings among Children, United States," *Vital and Health Statistics*, Series 11, No. 114, Public Health Service, Washington, D.C., March 1972; "Hearing Status and Ear Examination Findings Among Adults, United States, 1960-1962," *Vital and Health Statistics*, Series 11, No. 32, Public Health Service, Washington, D.C., November 1968; and "Hearing Levels of Children by Demographic and Socioeconomic Characteristics," *Vital and Health Statistics*, Series 11, No. 111, Public Health Service, Washington, D.C., February 1972.

Table 5.7

PERCENTAGE DISTRIBUTION OF PERSONS WITH BINAURAL HEARING IMPAIRMENT, BY CAUSE ACCORDING TO AGE AT ONSET: U.S., 1962-1963

Cause	All Ages	Under Age 6	Ages 6 to 16
Illness	20.9	33.2	41.7
Accident	13.5	6.5 ^a	11.5
Hereditary or congenital	4.0	24.9	4.0 ^a
Presbycusis (old age, degenerative)	4.9	NA	NA
Unknown	39.9	19.3	30.0
Other and nonresponse	16.8	16.0	12.8
Total	100.0	100.0	100.0

SOURCE: Augustine Gentile, Jerome D. Schein, and Kenneth Haase, "Characteristics of Persons with Impaired Hearing, United States: July 1962-June 1963," *Vital and Health Statistics*, Series 10, No. 35, Public Health Service, Washington, D.C., April 1967, pp. 35-36, Table 16, abstracted.

NOTE: NA = not available.

^aData do not meet standards of reliability and precision.

Because of these limitations, we rely primarily on other sources—special studies and medical textbooks for the most part—for information on prevalence of hearing disorders by age, etiology, and affection.

Hearing loss appears to be directly related to other conditions, such as mental retardation,³⁵ cerebral palsy,³⁶ cleft palates,³⁷ allergies,³⁸ goiter,³⁹ tonsillitis,⁴⁰ and vitamin deficiency.⁴¹ Our general recommendation for the creation of high-risk registers as an integral part of a strengthened identification program (Chapter 4) would at least be a start toward finding and preventing hearing loss in children known to possess other related conditions.

The need for detailed, timely, and improved prevalence data by etiology is clear. (This observation holds for vision handicapped children as well.) Detailed prevalence data would go a long way toward informing and rationalizing research priorities and medical service planning. Adequate information also might be usefully employed in informing pediatricians. For instance, if there is an upswing in the number of

³⁵ C. Webb et al., "Incidence of Hearing Loss in Institutionalized Mental Retardates," *American Journal of Mental Deficiency*, Vol. 70, 1966, pp. 563-568.

³⁶ W. Hatchuel, "The Importance of Performing Adequate Hearing Tests in Children with Cerebral Palsy," *South African Medical Journal*, Vol. 36, 1962, pp. 237-238.

³⁷ D. J. Fahey, "Otologic Care of Cleft Palate Cases," *Laryngoscope*, Vol. 75, 1965, pp. 570-587. In an interesting, comprehensive, multidisciplinary cleft palate program currently under way at Los Angeles Children's Hospital, as many as 75 percent of those enrolled contract disorders capable of causing hearing loss if not properly, correctly, and persistently treated. Interview, Dr. Frederick Linthicum, Otologic Medical Group, Los Angeles, December 14, 1973. This is a startling and not generally known finding.

³⁸ Hallowell Davis and S. Richard Silverman, *Hearing and Deafness*, Holt, Rinehart and Winston, New York, 1970 ed., pp. 106, 114.

³⁹ W. R. Trotter, "The Association of Deafness with Thyroid Dysfunction," *British Medical Bulletin*, Vol. 16, 1960, pp. 92-98.

⁴⁰ John Jacob Ballenger, *Diseases of the Nose, Throat, and Ear*, 11th ed., Lea and Febiger, Philadelphia, 1969, pp. 206-216; and L. G. Waggoner, "Secretory Otitis Media," *Harper Hospital Bulletin*, Vol. 22, 1964, pp. 50-58.

⁴¹ A. Yassin and M. Taha, "Sensory Neural Deafness in Pellagra," *Journal of Laryngology*, Vol. 77, 1963, pp. 992-1000.

children in a region or locality suffering from a specific disorder, it is important for pediatricians to know about it and be on the alert; persistence of the disorder signals that perhaps something more fundamental is happening to the population and warrants more detailed investigation. Finally, better information on prevalence could be converted into educational materials for the average parent, e.g., information on the signs of serous otitis media, what the parent should do, and what might happen if early and correct care is not undertaken.

Hearing Disorders: Description and Medical Treatment

This section briefly sketches some of the more common hearing disorders affecting children, and mentions common treatment methods. It also comments on the likelihood of successful treatment or prevention. None of what follows pretends to be definitive; the interested reader is strongly encouraged to consult the general sources listed in the footnotes for more detailed information.

Prevalence data on etiology are not sufficiently detailed to give one a very good idea about relative rates of occurrence and expectations of a handicapping condition resulting from any given disorder; the ordering of specific disorders in what follows therefore does not represent relative prevalence.

Serous otitis media. Serous otitis media is perhaps the most commonly encountered ear disorder in younger children. It has been implicated in a large fraction of the cases of hearing impairment, although we do not know what that fraction might be, given the poor quality of data available on hearing disorders in children. The term "serous otitis media" describes the collection of fluid in the middle ear, and it may be acute or chronic. The disorder is caused by any condition that results in blockage of the eustachian tube and may be congenital, due to infection or allergy, or may be caused by enlarged adenoids. In any event the middle ear becomes partially closed and gases in it are partially absorbed. This situation leads to a collection of fluid and infection in about 25 percent of the cases.

Treatment depends on the specific causative agent. For congenital causes, such as an immature eustachian tube, treatment may be continuous until the child matures or "grows out of" the disorder's cause; in the case of cleft palate, the prognosis is not so simple and probably will call for a great deal of specialized attention in the child's life. For most cases, one treats the underlying disorder; aspiration of the middle ear fluid may be required; myringotomy (incision of the eardrum) is frequently resorted to and with it the placement of a hollow plastic tube to prevent the incision from healing and to insure that the middle ear is open. In the case of allergic causes, one works to identify the allergic material, treats the condition through avoidance or desensitization, and simultaneously works to keep the middle ear from becoming or staying infected. Medication alone often suffices to open and clear the ear, as in the case of antihistaminics, decongestants, and mechanical techniques to inflate the passageway to the middle ear. Failure to treat properly may result in hearing loss.

Prognosis for treatment administered by competent physicians is nearly 100 percent success for all cases except cleft palate. In the case of myringotomy, however, there may be repeat surgeries to replace the ventilation tube. In a relatively few cases, it may become necessary to perform a mastoidectomy, a more radical procedure, to insure control or elimination of the serous otitis media.⁴²

⁴² B. Senturai, "Classification of Middle Ear Effusions," *Annals of Otolaryngology, Rhinology, and Laryngology*, Vol. 79, 1970, pp. 358-370; G. Thomas, "Management of Chronic Middle Ear Effusion," *California Medicine*, Vol. 110, 1969, pp. 300-304; H. Silverstein et al., "Eustachian Tube Dysfunction as a Cause for Chronic Secretory Otitis with Children," *Laryngoscope*, Vol. 76, 1966, pp. 259-273; and Ballenger, *op. cit.*, Chapters 44 and 45.

Acute otitis media and mastoiditis. A more serious variant of serous otitis media, this disorder is the inflammation and infection of the middle ear and the mastoid air cell system by one of several agents, e.g., pneumococci, streptococci, staphylococci, viruses, and *Hemophilus influenzae*. It is important to mention these disease agents, for proper treatment requires that the infection be cultured and the appropriate antibiotic be administered in sufficient strength and for a sufficiently long time to control the disease. Treatment is of primary importance because of the numerous, and mostly unpleasant, complications that may occur in the unchecked case of acute otitis media, e.g., meningitis, abscesses, mastoiditis, and hearing loss. With adequate care, which is mainly the selection and application of the appropriate antimicrobial agent and the administration of oral and topical decongestants, prognosis and the odds of cure are virtually 100 percent. The key is in continuous and competent treatment.⁴³

Chronic otitis media and mastoiditis. This form of otitis media results from infection of the middle ear and the mastoid via the eustachian tube or the external auditory canal; it may also result from the formation of a cholesteatoma, a "bone-like" cystic growth in the ear (considered below). Water is often found to be the main cause of the chain of events leading to infection, entering either through the external auditory canal or through infected droplets driven into the ear when sneezing or blowing the nose. As with other forms of otitis media, the basic problem is to control the disorder to avoid damaging complications. Chronic otitis media may form granulations and polyps, which in turn may break down the bony structure around the middle ear, which in turn could lead to abscess in the brain, meningitis, or infection of the labyrinth in the ear.

Treatment of chronic otitis media is both preventive and therapeutic: one should not blow the nose hard, sneezing should be done with an open mouth, and swimming and bathing should be done only with a cotton plug covered with vaseline or with a lambswool plug in the affected ear. Debris in the ear should be periodically removed. Topical applications of corticosteroids and specific antibiotics (determined after the infection is cultured and identified) are normally recognized as treatments of choice. As soon as the infection is controlled, and this may take as long as six or more months of careful management, it may be necessary to reconstruct the ear surgically, a procedure usually not undertaken until the patient is around 6 to 9 years of age, when the likelihood of upper respiratory infection declines.

With proper and persistent treatment, cure and prevention of hearing impairment should be nearly 100 percent. It should be stressed, however, that treatment for serous otitis media in general is not a "one-shot" process, and some cases may require repeated visits and surgeries. These are the facts of the disorder and they should be reflected in medical treatment and assistance programs and provisions.⁴⁴

Otitis externa. Otitis externa is basically a skin disorder. Infection is introduced into the ear, where the eardrum (tympanic membrane) may become infected and softened with bacterial growth. This growth, if unattended, may spread to the lymph nodes and other surrounding tissue or may perforate the eardrum. Treatment consists of removing the softened tissue, and the administration of anti-

⁴³ M. M. Rubenstein, "The Treatment of Acute Otitis Media in Children," *American Journal of Disabled Children*, Vol. 109, 1965, pp. 308-313; E. H. Townsend, "Otitis Media in Pediatric Practice," *New York Journal of Medicine* 1964, pp. 1591-1597; and W. Hemenway et al., "Treating Acute Otitis Media," *Postgraduate Medicine*, Vol. 47, 1970, pp. 110-115, 135-138.

⁴⁴ J. Frederickson, "Otitis Media and Its Complications," *Archives of Otolaryngology*, Vol. 90, 1969, pp. 387-393; R. E. Jordan, "Secretory Otitis Media in Etiology of Cholesteatoma," *Archives of Otolaryngology*, Vol. 78, 1963, pp. 261-264; Ballenger, op. cit., pp. 646-655; and James L. Sheehy, "Surgery of Chronic Otitis Media," *Otolaryngology*, Vol. 2, Harper and Row, Medical Department, Hagerstown, Md., 1972, Chapter 10.

crobial drops and systemic antibiotics (based on a culture and identification of the infectious agent). "Cure" is possible in about 95 percent of the cases, if treatment is properly administered and continuous care is given. The disorder has a persistence and rate of recurrence that may involve repeated care through adulthood.⁴⁵

Perforation of eardrum (tympanic membrane). Eardrum perforation can be caused by a number of factors and agents, such as trauma or acute otitis media. In rare cases, scarlet fever and rheumatic fever have been linked to perforations. Treatment consists of keeping water out of the ear to control and prevent infection, removal of softened tissue, and repeated application of topical anti-infectives. When the infection, if present, has been controlled, surgery may be called for to repair the drum, to prevent reinfection, and to improve hearing. In approximately 50 percent of the cases, cure will be "spontaneous" merely with the appropriate administration of antibiotics; however, in many of the remaining cases, surgery will be required to repair the damage. Surgery is successful in nearly all cases; hearing impairment will be mild but not disabling in some 25 percent of the cases and there will be no measurable impairment in the other 75 percent. The success rate of treatment depends on careful and correct management of the infection, if that is the cause, and then upon skillful surgery by a qualified otologist.⁴⁶

Bullous myringitis. Blisters will sometimes form on the eardrum itself in conjunction with an upper respiratory infection. The disorder produces extraordinary pain in most cases until the blister(s) rupture. The disorder is treated more or less symptomatically, e.g., through using local heat and hydroscopic and anaesthetic drops. The likelihood of successful treatment is nearly 100 percent. Surgical rupture of the blisters is *not* recommended because of the chance that infection may be spread to the sterile middle ear.⁴⁷ This disorder threatens the patient's hearing only if left untreated (and even then the probability of complication is slight) or if treated improperly (with subsequent infection of the middle ear).

Labyrinthitis. The inner ear may become inflamed through infection of the middle ear, surgical accidents, or meningeal infections (from nerve bundles connecting the ear with the brain). Nausea, vertigo, and general loss of balance are all common symptoms of labyrinthitis. Treatment consists of bed rest, medication to control motion sickness, and antibiotics to control the infection. Corticosteroids are sometimes used to reduce the inflammation. Unless untreated or improperly treated, cure should be virtually assured without hearing impairment.⁴⁸

Mumps. Mumps can cause deafness, as can other infectious diseases of childhood. (Scarlet fever, typhoid fever, diphtheria, etc., have been brought under control and cause very little hearing disorder in modern settings.) Basically, the viral agent attacks the Organ of Corti and other segments of the inner ear, destroying the tissue. As a result, very little can be done medically to restore hearing, although if nerve involvement has not been too great, sensory aids and rehabilitation can be of great assistance in reducing the handicapping of the condition. Prevention is the best course, however; and one should get the appropriate vaccinations.⁴⁹

⁴⁵ "Otitis Externa," *British Medical Journal*, Vol. 1, 1969, pp. 70-71; E. H. Jones, *External Otitis: Diagnosis and Treatment*, Charles C. Thomas, Springfield, Illinois, 1965; and Ballenger, op. cit., pp. 606-613.

⁴⁶ P. H. Beales, "Acute Otitis Media," *Practitioner*, Vol. 199, 1967, pp. 752-760; E. L. Derlacki, "Repair of Central Perforations of the Drum," *Archives of Otolaryngology*, Vol. 58, 1953, pp. 405-417; and Kempe et al., p. 228.

⁴⁷ B. Palmer, "Hemorrhagic Bullous Myringitis," *Ear, Nose, and Throat Monthly*, Vol. 47, 1968, pp. 562-565.

⁴⁸ See Ballenger, op. cit., Chapter 48, where the disorder is treated mainly as a complication of other ear disorders.

⁴⁹ Kempe et al., op. cit., p. 232; and Davis and Silverman, op. cit., pp. 120-122.

Measles and other viral agents. Measles and other viral agents have been implicated in hearing loss; in fact, in the 1920s and 1930s, meningitis was the commonest clearly identified cause of acquired deafness in children. Vaccines and antibiotics have changed this drastically, with the one exception that certain of the antibiotics that are effective in treating the primary disorder are themselves capable of damaging the inner ear and hence causing deafness. If treatment of the viral agent is not done in a timely fashion, bilateral hearing impairment usually results.⁵⁰

Eighth nerve tumors. Fortunately rather rare, although exact prevalence data are not available, tumors in the area of the inner ear are capable of producing sensorineural hearing loss and, if left untreated, weakening and damage of facial muscles and nerves, and death. If the tumor is detected early enough and is sufficiently small, it may be surgically removed. Morbidity and mortality from large tumors are both quite high. Diagnosis is a complex operation involving x-rays, audiometry, and other clinical findings.⁵¹

Cholesteatoma. When debris from the surface of the ear finds its way into the middle ear or mastoid following a perforation of the drum, a skin-lined cystic growth filled with hardened debris—cholesteatoma—may result. There are three general types, and treatment depends upon early and accurate diagnosis. In the congenital type, cystic growths are present in the temporal bone or in the mastoid at or near birth. In the primary acquired type, entrance through a perforation of the ear drum of hardened debris then develops into a growing cystic mass; in the secondary acquired type, entrance is much the same as the primary, although the continuity of the growth is not notable as with primary. Infection is a decided possibility either in conjunction with the cholesteatoma or as a result of degeneration of the bone invaded by the disease. Diagnosis is complex and involves radiography of a highly specific variety.

Treatment of the disease involves surgical removal and reconstruction. Control of the disease and the likelihood of successful treatment are highly dependent upon early detection and surgical technique. It is unusual for one suffering from the disease to escape without some hearing loss, although in specialized facilities control of it may be as great as 95 percent. Removal of the mastoid and repair of the eardrum, the common treatment of choice, will in most cases result in normal or slightly reduced hearing in some 10 to 25 percent of the cases, moderate, but usable hearing in about 50 percent of the cases, and moderate but acceptable hearing with the proper sensory aid in the remainder. Here again, the success of surgery and hearing conservation is critically dependent upon early identification, correct diagnosis, and skillful treatment.⁵²

Foreign bodies lodged in the ear. An incredible variety of foreign objects can find their way into the ear. Irrigation will remove something like 50 percent of them, and simple surgical removal the rest. Success of treatment is nearly 100 percent, with the warning that inept efforts to remove the offending object are themselves a possible source of serious damage to the ear. For instance, beans (often used as fillers in children's toys) should not be irrigated with water because they swell when moist. And children being worked on without anaesthesia occasionally jump and hence cause injury. Sufficient cases of damage are known to make note

⁵⁰ Davis and Silverman, *op. cit.*, p. 120.

⁵¹ Ballenger, *op. cit.*, pp. 764-767, and W. H. House, "Transtemporal Removal of Acoustic Neurinomas," *Archives of Otolaryngology*, Vol. 80, 1964, pp. 599-756.

⁵² Ballenger, *op. cit.*, pp. 648-652; and interview with Dr. Frederick Linthicum, Otologic Medical Group, Los Angeles, December 14, 1973. Treatment may be spread out over a one-year period and progress in several surgical steps.

of these "simple" problems. Well-meaning but unskilled efforts to remove the foreign body should be resisted.⁵³

Cerumen. Some people are predisposed to produce excessive cerumen secretions (wax) in the ear. If not removed, wax can restrict and even close the ear canal and apply pressure to the ear drum. In single episodes, treatment, consisting of removal of the debris and irrigation of the canal, is virtually 100 percent certain of restoring the ear to health. Some people have a chronic problem with cerumen, however; for them, treatment is more one of "control" than a "once-and-for-all" proposition and may be required at unpredictable intervals through their lives.

Trauma to Organ of Corti. Skull fractures in and around the auditory canal and the middle and inner ear may cause permanent and total hearing loss. Concussion without fracture can also cause some hearing loss, which sometimes is not permanent. It is impossible to assess the likelihood of hearing loss in general, as it is basically a function of the extent and location of the fracture or the severity of the concussion.⁵⁴ Observation is certainly required, including competent diagnosis, and surgery may be indicated to repair the fracture.

Drug effects on the auditory nerve. Several drugs are known to cause deafness by attacking and causing permanent injury to the Organ of Corti. Quinine, sometimes used to induce abortion, or even to induce labor by unknowing obstetricians, can cause irreparable damage. Certain antibiotics, primarily in the mycin group, are also known to cause deafness and hearing loss. Susceptibility to hearing loss varies from patient to patient, and loss may not be spontaneous but may occur at some time after the drugs have been administered. One otologist respondent in this study went so far as to recommend that antibiotics, particularly the mycins, be administered only in "life-threatening situations with continuous monitoring of kidney function to insure that toxic levels of the drugs had not been achieved." Very little can be done once the nerve has been damaged in this fashion, short of rehabilitative therapy.⁵⁵

Hearing loss due to noise. Temporary hearing loss is known to nearly everyone, from such causes as working around noisy industrial equipment, being near a discharging firearm, or riding a "go-cart" or motorcycle for some period of time. Usually, hearing returns to normal within a few hours or days; however, explosive sounds or continuous exposure to excessive noise can cause permanent hearing loss, as in the cases of rock musicians, children who persist in playing records at peak volume, and children who have cap pistols fired close to their ears. Treatment involves removal of the offending sound source or wearing of ear plugs, and rehabilitation. Because it involves the deterioration of the hair cells and nerve, surgical treatment is not possible. Persons already having some hearing impairment should be cautioned about exposure to loud and excessive noise over a period of time.⁵⁶

Hereditary or congenital hearing disorders. The term "congenital" literally means "at birth," although in common statistical usage the term has lost much sharpness of meaning: many instances are known where a child's impairment is called congenital, but in fact was the result of some infectious agent attacking the ear in infancy (e.g., meningitis) or of the injudicious use of antibiotics with damage occurring some time later. A few of the better known congenital disorders are listed and described below.

⁵³ B. M. Merkel, "Foreign Bodies in the Ear Canal," *Journal of the Iowa Medical Society*, Vol. 47, 1957, pp. 744-746.

⁵⁴ H. Schuknecht, "Head Injury," *Archives of Otolaryngology*, Vol. 63, 1956, pp. 513-528.

⁵⁵ James L. Sheehy, "Ototoxic Antibiotics," *California Medicine*, Vol. 94, 1961, pp. 363-365.

⁵⁶ Davis and Silverman, *op. cit.*, pp. 114-119.

Maternal rubella: As is described in detail in Chapter 6, maternal rubella, particularly when contracted in the first three months of pregnancy, is capable of causing an insidious assortment of handicaps, not the least of which is congenital hearing impairment of often marked severity. Ex post facto, there is no treatment except rehabilitation.

Congenital malformations of the Organ of Corti: Two basic classes of this disorder exist: hereditary and "misadventures of fetal life." In the first class, it is thought to be transmitted by a recessive gene in the more common case, and by a dominant gene which also is linked to kidney malformations. Both cases result in bilateral and severe impairment. Misadventures include maternal rubella, administration of ototoxic drugs (as noted above), and damage from other, unspecified, viral agents. A number of specific syndromes have been identified describing specific ways in which the Organ of Corti and the inner ear may be malformed and dysfunctional, e.g., Waardenburg, Mondini-Alexander, and Schiebe. As with other inner ear disorders, treatment prospects are not good. The major concern is to identify the child as soon as possible to insure that rehabilitation progresses as well as possible.⁵⁷

Erythroblastosis fetalis: As a result of Rh sensitivity, the infant may suffer from hearing loss. The critical combinations are an Rh-positive father and an Rh-negative mother. Particularly in second and subsequent births the condition, commonly known as "newborn jaundice," can attack the central nervous system through a protein reaction, and the auditory system is susceptible to the disorder. Treatment is massive transfusion of the infant, e.g., "exchange transfusion" if indicated by serum bilirubin level, and placement of the infant on a high-risk registry for subsequent close examination, early identification, and appropriate rehabilitation. Lowered oxygen levels in the blood aggravate the problem. Prevention is partly possible through inoculation of the Rh-negative mother with an anti-Rh antibody.⁵⁸

Stenosis and atresia of external auditory canal: A narrowed canal may be caused through infection or may be congenital. In the former case, treatment consists of removal of the infection and the debris it leaves, and repair of any damage done to the canal or the middle ear. Damage may also result from surgical misadventure. Repairing the damage requires a highly skilled technique but is successful in approximately 90 percent of the cases. Depending upon the seriousness of the narrowing and damage, there may be no hearing loss at all, but occasionally moderate impairment results (especially in the congenital case). Bone-conduction hearing aids and prompt rehabilitation should alleviate the handicap.⁵⁹

Congenital malformation of the ear drum: There may be congenital malformations of the external ear, the auditory canal, and the eardrum, in which all or part of any or all of these items is missing or deformed. Surgical restoration is usually called for if the disorder is bilateral; if unilateral, surgery may be postponed because of possible damage to the facial nerve. Success rates depend largely on the degree and site of the malformation; likewise, hearing loss depends on the severity of the disorder and the success of restorative efforts.⁶⁰

⁵⁷ H. Davis, "The Young Deaf Child: Identification and Management," *Acta Oto-Laryngologica*, (Supplement), Vol. 206, 1964, pp. 1-258; Ballenger, op. cit., pp. 769-773; and Kempe et al., op. cit., pp. 231-232.

⁵⁸ Davis and Silverman, op. cit., pp. 122-123; J. G. Hall, "On the Neuropathologic Changes in the Central Nervous System Following Neonatal Asphyxia with Specific Reference to the Auditory System in Man," *Acta Oto-Laryngologica*, (Supplement), Vol. 188, 1964, pp. 331-338; and C. Friedman, *Rh Isoimmunization and Erythroblastosis Fetalis*, Appleton-Century Crofts, New York, 1969.

⁵⁹ Ballenger, op. cit., pp. 600-613; David D. De Weese and William H. Saunders, *Textbook of Otolaryngology*, C. V. Mosby, St. Louis, Missouri, 1968 ed., pp. 345-346, where the Treacher-Collins syndrome is discussed; and Kempe et al., op. cit., p. 225.

⁶⁰ James A. Crabtree, "Tympaanoplastic Techniques in Congenital Atresia," *Archives of Otolaryngology*, Vol. 88, 1968, pp. 89-96.

Otosclerosis: Because of abnormal bony growth, usually at or nearby the stapes or stirrup, hearing gradually becomes impaired. Otosclerosis is hereditary and occurs more commonly in females. It is rare for the disorder to manifest itself before about the age of 15 years. For those whose nerve has not been involved, surgical treatment is possible and successful in between 80 and 90 percent of the cases. Depending upon the extent, if any, of nerve involvement, hearing can be totally restored. Repeated operations in the case of initial nonrestoration have been successful.⁶¹

Treatment of Hearing Disorders in General

Many, if not most, external ear, eardrum, and middle ear disorders are treatable with a high likelihood of success in correcting or avoiding a handicapping condition. The critical factors are early identification, correct diagnosis, and skilled treatment. Most sensorineural ("nerve deafness") disorders are not so successfully treatable, and the likelihood of a lifelong handicapping condition is much greater. The key factors in sensorineural disorders are early identification, stabilization or cure of the underlying disorder, if appropriate and possible, and then vigorous rehabilitation to minimize the handicapping effects of the disorder. The need for better data relating the disorders to etiologies is critical. It is difficult to assess the medical prevention and treatment needs of the population based on their disorders alone. And planning to meet those needs as they change over time is even more difficult without data on the prevalence of etiologies.

Medical Treatment Costs of Hearing Disorders

A sample of treatment costs for medical services available to those suffering from hearing disorders is presented in Table 5.8. These data are a sample of current charges for high-quality care in a specialized otologic practice, and may vary considerably for different parts of the country and for different practices. These estimates are for professional otologist's fees only; payment for other aspects of medical care such as days of hospitalization are excluded.

As with vision disorders, Table 5.8 makes it apparent that high-quality medical care can be had, and can also be costly in the absolute sense. Again, however, the appropriate trade-off is between the cost of such care and all costs involved in a lifetime of being handicapped or more severely handicapped than one would be with good medical care. In this sense, medical treatment is probably a "bargain." We should also call attention to the discrepancy between this fee schedule and the top fees payable under federally supported medical treatment programs. Many of the fees in Table 5.8 exceed maximum governmental program limits. Finally, we repeat the observation that the finest specialized medical care in the world is relatively useless, irrespective of its costs, if local identification and diagnosis services are inadequate.

Overview of Medical Service

A significant number of potentially handicapping disorders can be prevented, reduced, or eliminated altogether with skilled medical treatment. The major problem is not the quality of medical treatment, but the fact that so many handicapped

⁶¹ Otologic Medical Group, *A Discussion of Otosclerosis*, Los Angeles, 1972 (pamphlet); Kempe et al., *op. cit.*, p. 229; and Ballenger, *op. cit.*, Chapter 49.

Table 5.8

SAMPLE TREATMENT COSTS FOR HEARING DISORDERS IN CHILDREN, SPECIALIZED PRACTICE, CALENDAR YEAR 1973

Item	Charge (\$)	Item	Charge (\$)
Service group/routine/MDs		Miscellaneous and office procedures	
Office visit	12 ^a	Myringotomy, unilateral	40 ^e
Initial comprehensive diagnostic otologic examination	35	Myringotomy with tube, unilateral	50 ^f
Initial hospital consultation	35	Myringotomy with tube, bilateral	80 ^g
Routine hospital visit	12	I.V. histamine	15
Diagnostic group/X-ray		Injection	5
Plain mastoid	35	Medication	(h)
Plain sinus series	35	Surgical nurse	50
Polytome mastoid X-ray	80	Special reports	(h)
Polytome otologic survey	60	Surgical procedures ⁱ	
Poly-petrous pyramid X-ray	80	Myringotomy, unilateral	150 ^j
Skull, complete	35	Myringotomy, bilateral with tube	200 ^j
Pelvic scan	5	Myringotomy, unilateral with tube	150 ^j
Implant series	60	Adenoidectomy	100
Diagnostic group/laboratory		Tonsillectomy	200
Culture sensitivity	10	Myringoplasty	800
Blood count, complete	5	Revision of myringoplasty	(k)
Protein, total serum, chemical	8	Mastoidectomy, simple	800 ^l
Child's panel	36	Mastoidectomy, radical	1000 ^l
Hydroxycorticosteroid (17 OHCS)	36	Mastoid obliteration	1000 ^m
Lipoprotein phenotypes	25	Mastoidectomy, mod. radical	1000 ^m
Diagnostic/audiology		Revision of mastoidectomy	(k)
Initial hearing test	15	Stapes mobilization	1000
Return hearing test	10	Stapes exploration	1000
Unilateral speech	5	Stapedectomy	1000
Bilateral speech	10	Revision of stapedectomy	(k)
Bekesy unilateral SISI	15	Stapes fenestration	1000
Bekesy bilateral SISI	25	Revision of stapes fenestration	(k)
Tone decay	5	Tympanoplasty without mastoidectomy	1000 ⁿ
Hearing aid evaluation	35	Revision of tympanoplasty without mastoidectomy	1000 ⁿ
Hearing aid test/check	20	Tympanoplasty with mastoidectomy	1200 ⁿ
Special audiologic evaluation	50	Tympanoplasty with revised mastoidectomy	(k)
SISI only	5	Revised tympanoplasty with mastoidectomy	(k)
Stenger test	10	Labyrinthectomy TR/canal	600
Recruitment test	5	Labyrinthectomy TR/lab	900
Impedance test	10	Vestibular nerve sec TL	1000 ^o
Delayed feedback	15	Vestibular nerve sec MF	1500 ^o
Electrical promontory testing	250	Facial nerve repair	1500
CROS evaluation	10	Facial nerve graft	1500
Diagnostic vestibular testing		Facial nerve decompression	1000
Electronystagmography	35	Shunt--optic/periotic	700 ^o
Eng positional	15	Biopsy of eac.	250
Eng interpretation and report	15	Petrosectomy	1500 ⁿ
Special vestibular testing	(b)	Cholesteatoma removal, primary	1500 ⁿ
Diagnostic/allergy testing and treatment		Exostosis, removal	700
Terpene and Petro tests	55	Tumor removal, glomus jugular	2500 ^p
Terpene or Petro retest	6	Tumor removal, glomus tympanicum	1500 ^p
Complete allergy test	230	Tympanotomy	(k)
Allergy injection	5	Tympanosympathectomy	(k)
Allergy medication	10 ^c	Meatoplasty	(k)
Histamine titration	10	Oval window fistula repair	(k)
TOE/dust/inhalants	50	Acoustic neuroma, removal	2500 ^p
Pollen and inhalant testing	115		
Foods testing	115		
Recheck pollen and inhalation	50 ^d		
Recheck individual food	6		

^aFactor used in calculation of repeat visits.

^bNo maximum fee.

^cMinimum; no maximum fee.

^dFor each food tested.

^ePlus \$25 for subsequent visits.

^fPlus \$35 for subsequent visits.

^gPlus \$60 for subsequent visits.

^hSpecial charge.

ⁱBasic fee covers all procedures, including 6 months of postoperative care; any additional fees required are noted.

^jPlus 6 postoperative office visits = \$72.

^kFee varies.

^lPlus 2 postoperative office visits per year for life to clean cavity.

^mPlus 2 postoperative office visits per year for life.

ⁿPlus 3 postoperative office visits.

^oFee varies around average.

^pPlus 8 postoperative office visits.

children are not receiving it. Lacking early identification, accurate diagnosis, and timely direction, the best medical treatment in the world may well be practically and tragically irrelevant.

Many of the disorders causing vision and hearing handicaps, even the more exotic of them requiring highly specialized attention, can be treated at remarkably low cost relative to the expected lifetime costs incurred by a handicapped person. On cost grounds alone, a convincing argument often can be made that the best medical treatment available represents a profitable social investment, since it reduces future claims on society and the public treasury. To deny or limit these services is to risk being penny-wise and pound-foolish. Add to the cost-argument even the most elementary humanitarian concerns, and the case for providing medical services to those who need them becomes virtually incontrovertible.

The limited and inelastic population of gifted and highly skilled physicians could be better utilized than it presently is if the population in need were actively identified (see Chapter 4) and if the "invisible intelligence network" currently linking the population with doctors were made visible through an improved direction service concentrated at the regional level. (See our recommendations in Chapter 3.) Effective direction could overcome the consumer's ignorance of where to get appropriate medical care; and adequate National Health Insurance for all citizens, together with other supplementary services such as transportation, could surmount the economic deterrent.

The provision of good medical care to the nation's handicapped youth is not a "blue sky" objective. The trade-off, in rational terms, is between lifetime quality-of-life and economic costs for a permanent disability and possibly one-time and relatively limited costs for proper medical treatment, with all that might entail for the aggregate reduction in the number and extent of handicapped persons in the population.

Medical Treatment Service Recommendations

The following recommendations are in addition to those made earlier in the medical programs section of this chapter.

Prevalence data on the status and needs (medical treatment and other needs) of the sensorially handicapped population are in disarray; a great deal of vigorous activity is called for to correct this deficiency.

- The Department of Health, Education and Welfare (the proposed Office for the Handicapped or the Office of the Assistant Secretary for Planning and Evaluation) should institute a thorough and continuing periodic review of current data-collection and utilization procedures and resources with respect to handicapped children. This would be a first important step in improving services to the handicapped generally, with the intent of implementing steps to improve the availability and use of information. The National Eye Institute, the National Institute of Neurological Diseases and Stroke, and the Bureau of the Census, among others, should be consulted with an end in view of preparing a segment of questions on medical and other services to the handicapped population for inclusion in the 1980 Census of the population. Improved information could do much to inform legislative and executive agency actions affecting, ultimately, the lives of the handicapped population. Information does not presently exist in the quantity, in the form, or with the reliability necessary to accomplish this critical task.

Prevailing fee schedules used in government-funded medical programs are often significantly less than the going rates for identical privately funded treatment. Medical costs are highly variable, and some highly qualified physicians are now avoiding acceptance of Medicaid and CCS patients.

- Medical fee payment schedules should be revised to reflect the realities of the medical marketplace. National Health Insurance proposals represent one mechanism for rationalizing the fee schedules.

Treatment methods vary from the most highly specialized ophthalmologic and otologic practices to general practices found through the country. The Department of Health, Education and Welfare could accept responsibility, in the form of an emphasized catalytic role, to keep abreast of improvements in medical treatment to the hearing and vision handicapped population and then to help insure that these improvements are diffused throughout the national context.

- With an improved research management information system, the proposed Office for the Handicapped or NEI and NINDS could lead such catalytic activities by identifying promising research findings and then stimulating the development work required to make these research findings of general, practical use. No one at the federal level currently has prime responsibility to insure that research results are developed and disseminated in such a fashion, with the result that the process, if it occurs at all, is protracted unnecessarily. In-service training of specialists who are not at the forefront of medical treatment knowledge is presently no one's responsibility.

Identification and direction are critical, missing elements in the timely delivery of appropriate medical treatment; any improvement in these two neglected services would have the certain result of reducing the total hearing and vision handicapped population, and lessening the degree of handicaps within that population through improved receipt of preventive and remedial services.

- Previous recommendations for the direction and identification services should be adopted as expeditiously as possible (see Chapters 3 and 4).

Chapter 6

PREVENTION

INTRODUCTION

This chapter discusses the prevention of hearing and vision handicaps in youth. It briefly summarizes current programs for the provision of prevention services; reviews the preventability of many sensory disorders; examines several prevention strategies; and presents recommendations for improvement.

Prevention is a neglected and seriously underused service. This neglect is costly both to society and to handicapped youth and their families, not only in money but in the tragic fact that a large fraction of the sensory handicaps occurring in youth could be prevented. That fraction may be as high as one-third or one-half; given the poor state of the data, no one really knows for sure. Prevention can be achieved as the direct result of improved services (such as timely identification of the disorder and proper medical treatment); as the direct result of immunization efforts; and indirectly as a result of improved prenatal care, family planning, genetic counseling, abortion, and other practices. Each of these strategies is discussed below.

In contrast to the nearly \$5 billion expended annually by all levels of government for service to all types of handicapped children, we are able to identify only some \$50 million specifically targeted for prevention activities for children; in other words, about 1 percent is targeted for prevention and 99 percent for service after the child is handicapped.¹ Figures for the sensorially impaired subset of the overall handicapped population generally mirror this breakdown.

If one in ten existing handicaps in youth had been prevented, the future savings to the government might have been about \$500 million per year for all handicapped youth, and \$42 million for sensorially handicapped youth. This represents, for each handicap prevented, over \$6000 in the cost of future government services (discounted at 8 percent) over only the first 21 years the youth has the hearing or vision handicap. The total value of the youth's increased quality of life due to not being sensorially handicapped is much more important, and may be worth at least 10 times that amount, or much more, depending on one's value judgment.

Our recommendations for improved prevention services follow.

Give a single federal agency prime responsibility and authority for prevention as a service. Studies should be conducted to collect much better information on prevention and to evaluate alternative prevention strategies for specific disorders to enable more informed policies. The few federal prevention research and operational programs that exist provide spotty coverage of the population, at best, and are scattered through various agencies. No single agency is primarily responsible for looking at prevention as a service, but the proposed Office for the Handicapped, for example, if well staffed and given sufficient authority, could orchestrate federal prevention efforts. Not only would it be desirable to rationalize research expenditures based on the needs of the population (particularly as it changes) and to exploit research findings with evaluations and demonstrations if called for, but basic cost-benefit analyses are needed to inform future resource debates about research versus treat-

¹ Rand Report R-1220-HEW, pp. 15-16. The precise level of funds targeted for prevention is a matter of definition, but the inescapable conclusion is that the level is very low.

ment and about prevention versus service after handicapping. The present lack of information and evaluation of prevention activities is extreme.

Revise and strengthen the rubella vaccination program, and provide funding for an open-ended period. The messages here are very clear: rubella can be prevented; many youth are not immunized; rubella-caused handicaps are prevalent, especially in youth whose mothers contracted the disease in the first trimester of pregnancy; and prevention is decidedly cost-effective in terms of reduced future service costs, not to mention the extremely important reduced quality-of-life effects of the handicaps. We recommend mandating rubella vaccination for all prepubescent females through a school-based program conducted under auspices of the National Center for Disease Control; creating a model code for state marriage license serologic screening practices with the objective of including an additional test for the presence of rubella antibodies; and appealing through the mass media and professional medical publications to encourage all childbearing females to obtain such tests from their private physicians.

Without deductibles, fully cover high-quality prenatal care, routine immunization services for children, eye and ear examinations for youth up to age 21, and preventive medical treatment, in Medicaid and in any National Health Insurance program that may be implemented. Adoption of this recommendation and those made in earlier chapters for early identification, direction, and medical treatment, is perhaps the most important means of preventing handicaps. High-quality medical care is available to prevent disorders and to prevent existing disorders from resulting in handicapping; the problem is the inadequate match between children in need and medical-technical resources.

CURRENT PREVENTION PROGRAMS

This section first discusses operational prevention service programs and then those oriented toward prevention research. Before discussing specific programs, however, it is useful to examine program goals as they relate to prevention activities.

Personal "nondependency" as a goal to which prevention relates has been formulated in the following terms by Elliott Richardson, former Secretary of Health, Education and Welfare:

... the non-dependency goal would suggest that our objectives should be: 1. to create prevention mechanisms which identify the likelihood of people sliding down the scale of personal freedom of choice and reliance on others, and which remove the dangers which threaten the status of those people
....²

The "likelihood" idea is related to prevention research activities, and the "removal of danger" idea with operational prevention service programs.

Another objective to which a prevention program can relate is to reduce expected public expenditure and quality-of-life disbenefits over the lifetimes of persons in the total handicapped population. Prevention can reduce future public expenditure by reducing the absolute number of those entering the handicapped population and by providing a full range of remedial and restorative services to those already in that population. Handicap prevention is not done well in the United States, as attested to by the persistent prevalence of sensorially handicapped persons with preventable

² "Planning Guidance Memorandum—1972," February 15, 1972.

etiologies (see Chapter 5), and by the simple and persistent statistic that the United States ranks fifteenth among nations in infant mortality.³ The provision of remedial and restorative services is not done very well either, as attested to by other chapters of this report.

If so many disorders are demonstrably preventable, why do so many handicapped children still enter the population because of them? If so many other disorders are suspected of being to blame for handicaps, why is research directed at the resolution of these disorders so poorly orchestrated?

S.H. King has advanced an explanation for the undervaluation of inoculation programs that may be applicable to prevention programs in general: "The person or group with a time orientation toward the present [e.g., politicians] will have difficulty in seeing the value of inoculations against disease, a future occurrence."⁴ Undervaluation may occur for the full range of prevention programs for the same reason.

Underinvestment in prevention services may also occur because those agencies currently administering prevention programs, usually health agencies or personnel, do not benefit from the future reduced costs of service such as special education, vocational services, and welfare. Thus, from the narrow viewpoint of the administering agency, rather than the viewpoint of all government agencies as a whole, prevention may be a net long-term as well as a short-term cost.

Seriously inadequate information also hampers and misdirects prevention services and research. Foggy information on the prevalence of various etiologies can produce only foggy estimates of the extent to which the individual disorders contribute to the handicapped population, and how these prevalences are changing over time. One result is that research attention focuses somewhat indiscriminately on both rare and commonplace diseases and disorders.⁵ Another result is that erratic information makes it hard to marshal compelling arguments for prevention.

Still other explanations may be: few theories relate prevention costs to other service costs (partly, no doubt, because of the paucity and imprecision of the basic information); known data on all other service costs are not routinely related to the immediate costs of conducting research into disorder causes and processes or to the operational costs of carrying out a prevention program; no one has direct and comprehensive responsibility for prevention; and insufficient attention is being given to the applications of research findings to prevention program operations and to dissemination of those findings to practicing physicians, who are a major source of prevention through proper medical treatment of handicap-causing disorders.

³ The current rate is 19.2 deaths before the age of 1 year per 1000 live births. On this measure, the United States is ranked behind Sweden (11.1/1000), Japan (12.4), France (14.4), the United Kingdom (18.0), Canada (18.8), East Germany (18.8), and others. *Scientific American*, Vol. 229, No. 3, September 1973, pp. 64-66. The contribution of adequate prenatal care (a preventive practice) was underscored in that report. A 1968 health survey found that the then-prevailing infant mortality rate of 21.9 for all of New York City could have been reduced to an estimated 14.7 if all the mothers surveyed had received a *modal* amount of prenatal care. For those in New York City judged to have received "adequate" prenatal care, the rate was 13.3, for "intermediate" care it was 18.5, and for "no" or "inadequate" prenatal care it was 35.8. It was concluded that there existed "a gross misallocation of services by ethnic groups when the risks of the women are taken into account."

⁴ *Perceptions of Illness and Medical Practice*, Russell Sage Foundation, New York, 1962, p. 53.

⁵ Jacob Feldman, *The Dissemination of Health Information*, Aldine, Chicago, 1966, has addressed the general question of data as it relates to rational decisionmaking on research expenditures and for prevention has concluded that the poor available information on the time of onset and etiology has inhibited concerted attention and remediation.

Operational Prevention Service Programs ⁶

Immunization is a clear instance of preventive service, for which there is a number of programs.

Communicable Disease Prevention and Control has been legislated through the basic Public Health Service Act and updated periodically by amendments.⁷ It includes the epidemiological program of the National Center for Disease Control, which had \$1.709 million in FY 1972 for consultation, technical assistance, and training for state health agencies, among other responsibilities; a communicable disease control program, funded at \$7.213 million in FY 1971, that offers a variety of immunization activities to children; and Health Service Development Project Grants to the states, which have supported, among other activities, the rubella immunization project at a rate of \$14.5 million and which allocated some \$500,000 for a modest but expanding program for Rh desensitization in FY 1973.⁸ Additionally, some number of immunization services and activities are conducted through the Maternal and Child Health Service.⁹

Venereal disease, an etiology linked to congenital sensorial disorders, is also a preventive responsibility of the National Center for Disease Control. It was funded at a \$16.0 million level in 1972.¹⁰

General prevention along a broad but not very deep front is provided under Maternal and Child Health and Crippled Children's Services programs.¹¹ A 1969 survey indicated that, for *all* services for *all* conditions, there were some 190 MCHS and 19 CCS supported program activities in the states that could be directly labeled "preventive."¹² Of this total, no single type of prevention service was provided in all the states, and the portion accruing to sensorially handicapped children is not clearly indicated or recoverable from the presented data. Table 6.1 lists other general preventive activities related to hearing and vision problems, but provides no dollar totals because of the manner in which the state program data are tabulated (expenditures are not linked with the program descriptions).¹³ Vision and hearing conservation programs of an unspecified nature accounted, respectively, for 15 and 29 MCHS and CCS program activities in the states.¹⁴

Medicaid has an operational prevention component inherent in its early and periodic screening, diagnosis, and treatment provisions, although the benefits related to sensorially handicapped children are reduced by the lack of full implementation of the provisions, and the fraction of the total effort devoted to prevention is unknown. (See the discussion of Medicaid in Chapter 5 above).

⁶ A grand total of \$153 million for *all* Federal "Preventive Health Services" is listed in U.S. Department of Health, Education and Welfare, *Justifications of Appropriations Estimates for Committee on Appropriations—FY 1973*, Vol. II, pp. 1-63.

⁷ Public Health Service Act, Secs. 301, 314, 317, 361-369. Bio-Dynamics, Inc., *Evaluation of the Rubella Immunization Program*, DHEW/ASPE, Contract No. HEW-OS-70-153, Washington, D.C., 1972, pp. 7-18, presents a thorough legislative digest.

⁸ *Justification*, p. 17.

⁹ Rand Report R-1220-HEW, Table 8.27.

¹⁰ *Update to the 1972 Catalog of Federal Domestic Assistance*, Office of Management and Budget (OMB), Washington, D.C., November 1972, p. 186.1.

¹¹ A narrative is contained in Edwin M. Gold et al., "Total Maternal and Infant Care: An Evaluation," *American Journal of Public Health*, Vol. 59, No. 101, October 1969, pp. 1851-1856.

¹² Rand Report R-1220-HEW, pp. 215-220.

¹³ *Ibid.*, pp. 214-215.

¹⁴ Many of these are integral parts of P.L. 88-156, including the Maternal and Infant Care Program (M&I). Arthur J. Lesser, in his "Accent on Prevention Through Improved Services," *Children*, Vol. 11, No. 1, January-February 1964, pp. 13-18, asserts that such programs have had the effect of reducing premature births, infant mortality, mental retardation, and neurological handicapping.

Table 6.1

NUMBER OF STATES HAVING PREVENTIVE SERVICES FOR VISION AND
HEARING DISORDERS: 1969 SURVEY

Maternal and Child Health Service and Crippled
Children's Service Programs and Activities

Program	Service and Number of States		
	MCHS	CCS	Total, Both Services
Rubella			
Studies of rubella	1	0	1
Specific studies for preventive care			
Lab studies, rubella test	6	0	6
Lab studies, rubella immunization	1	0	1
Lab studies, rubella register	<u>3</u>	<u>0</u>	<u>3</u>
Total, rubella	11	0	11
Immunization			
Children's immunization clinics	32	0	32
Provision of immunization supplies	<u>23</u>	<u>1</u>	<u>24</u>
Total, immunization	55	1	56
Genetics			
Specific services for genetics counseling	11	5	16
Specific services for genetics	5	1	6
Heritable metabolic diseases, screening and treatment	<u>12</u>	<u>5</u>	<u>17</u>
Total, genetics	28	11	39

SOURCE: Rand Report R-1220-HEW, Table 8.27, pp. 215-220.

The "Health Maintenance Act of 1973" is popularly regarded as a prevention initiative,¹⁵ but it cannot be reliably estimated how much the \$375 million total to be expended over the next five years will reduce sensorial handicapping in the young.

Finally, many other governmental programs include prevention as a secondary activity, but with unknown effects. In this class would be improved prenatal care; family planning; identification and direction, where they exist; and a few operational genetics counseling programs. While precise numbers cannot be estimated, the sum total of all such activities is relatively small.

Prevention Research Programs

Preventive research programs are a main responsibility of several institutes within the National Institutes of Health,¹⁶ but it is often difficult to say what portion of a research program on sensory impairment in general should be evaluated as a benefit to the young in particular. For example, research to promote the understanding, treatment, and prevention of glaucoma is universally beneficial, but one cannot say how much of the current glaucoma research budget of the National Eye Institute should be counted as a benefit for handicapped children.

The National Institute for Child Health and Human Development (NICHD), primarily through its perinatal biology and infant mortality program, and to a lesser

¹⁵ See, e.g., "Nixon Preventive Health Bill," *New York Times*, December 30, 1973, pp. 1, 13.

¹⁶ Rand Report R-1220-HEW, Chapter 9 has a more complete description. NIH research programs are also obviously relevant to medical treatment, as discussed in Chapter 5 of this report.

extent through its growth and development and population and reproduction programs, is conducting research contributing to the prevention of sensorial and many other types of handicapping. Perinatal biology and infant mortality represented a total expenditure of \$10.8 million in FY 1972 for research in 318 grants and contracts.¹⁷ Studies on maternal complications in pregnancy, toxemia and diabetes, malnutrition affecting the fetus, respiratory distress, Rh sensitivity, hypoglycemia, and erythroblastosis fetalis, all added to prevention.

The National Institute for Neurological Diseases and Stroke (NINDS) contributes to prevention research, mainly through its communication disorders prenatal and perinatal programs. Of the \$10.0 million spent on the former and \$7.5 million spent on the latter in FY 1973,¹⁸ some fraction benefitted aurally handicapped children. (In addition, NINDS funds a few nonchild-specific projects on prostheses for *blind* persons.)

The National Eye Institute (NEI) had a budget of \$24.95 million in FY 1973, broken down according to disease classes as follows: retina and choroid, \$6.2 million; sensory motor, \$3.7 million; corneal, \$3.0 million; glaucoma, \$2.7 million; and congenital and developmental, \$530,000.¹⁹ (The remainder went for operating expenses, the Model Reporting Area project, and miscellaneous activities.) Only the congenital and developmental expenditures are child-specific.

The National Institute of Dental Research (NIDR) conducts a cleft lip and palate research program, which was funded at \$2.0 million in FY 1970.²⁰ The correlation between cleft lip and palate defects and serous otitis media is known to be high (see Chapter 5); such research therefore has some preventive component for hearing handicapped children.

The National Institute of Allergy and Infectious Diseases (NIAID), supports research into methods of control of allergic, immunological, and infectious diseases, which contain many etiologies related to sensorial handicaps.

The National Institute of General Medical Sciences (NIGMS) supported genetic research with \$33.5 million in FY 1973, some portion of which aids prevention of aural and visual handicapping; the same is true for its programs on general clinical service and trauma.

Private research activities exist, but their total contribution to research is not known. One of the larger and better-known private organizations, however—Research to Prevent Blindness—contributed \$2 million to research in the period from 1960 through 1973, and granted another \$17 million for laboratory facilities during that period.²¹

Prevention Programs in General

Prevention is one of the more neglected services, and the up-and-down fortunes of prevention programs sometimes resemble "The Perils of Pauline." Crisis or the threat of impending crisis is often necessary to galvanize official government attention to the prevention service, with the result that prevention programs have been heavily oriented to specific diseases and often limited in duration and total funds expended.

¹⁷ NICHD, Program Statistics and Analysis Branch, Interview, June 7, 1973.

¹⁸ The perinatal program has over the years been conducting an extensive study of neurologically and sensorially handicapped children, resulting in a rich source of unique data. A great deal of potential knowledge is contained in this file, but much analytic work remains to be done to realize the full benefits from it.

¹⁹ Rand Report R-1220-HEW, p. 226.

²⁰ *Ibid.*

²¹ Research to Prevent Blindness, *Annual Report*, New York, 1973.

The record of prevention research into the causes and cures of sensorial handicapping in children is mixed and very difficult to piece together. Not only are the unpredictable vagaries of research operating, but the research itself is scattered among an assortment of institutions whose main order of business is often *not* research on sensorial handicapping. Furthermore, few institutional mechanisms exist to translate research findings into applied methods to prevent sensorial handicapping.

SOME PREVENTABLE SENSORY DISORDERS

A number of hearing and vision disorders can be prevented, as indicated in discussions of the disorders in Chapter 5. Table 6.2 is a partial listing of those disorders in which disabling sensory handicaps appear to be relatively more preventable, given the current state of the medical art.

Table 6.2
SOME DISORDERS AND DISEASES WITH HIGH PROBABILITY OF PREVENTION

Disorder or Disease	Handicap		Method
	Vision	Hearing	
Rubella	X	X	Immunization
Ototoxic deafness		X	Proper medical treatment
Noise deafness		X	Remove offending source; institute hearing conservation measures; keep children away from explosive sounds
Otosclerosis		X	Diagnosis and surgical treatment
Otitis media		X	Identify, diagnose, and treat correctly. Persistent care
Mumps		X	Immunization
Measles		X	Immunization
Meningitis		X	Prompt, proper medical treatment
Rh sensitivity		X	Proper identification and sound care
Retrolental fibroplasia	X		Proper medical treatment (specific case); prenatal care (general case)
Amblyopia, strabismus, myopia	X		Prompt identification, diagnosis and treatment
Cataract	X		Early detection and treatment
Glaucoma	X		Detection before irreparable damage is done; proper treatment
Retinoblastoma	X		Treatment of affected child. I.D. for parents-to-be suspected of being trait carriers, genetic counseling, and family planning

NOTE: For each disorder, high-quality preventive or medical treatment service is thought to result in no handicapping condition in at least three-fourths of the cases, and for some disorders, in at least 99 percent.

Rubella is preventable; an effective vaccine has been in widespread use since 1969, but implementation and scientific problems still impede full prevention (they are discussed under "Prevention Strategies" below).

Ototoxic deafness is known to result from the use of certain drugs, and others are suspected. For those known to cause hearing loss, prevention should be a near certainty, but is not. For those antibiotics suspected to be related to hearing loss, a clear case can be made for additional prevention research, an eventuality more or less assured in several noted programs. We know how to prevent handicapping from inappropriate drug use, but drug-deafened children still enter the population.

Any number of disorders, exemplified by various forms of otitis media, are liable to cause sensory deficits *if* they are improperly treated, left untreated, or treated late because of faulty identification, direction, and treatment services.

Retrolental fibroplasia can be devastating, but it is generally known that excessive oxygen is responsible for the blindness it causes. Even at the current state of knowledge, a majority of the people entering the population of those blinded by RLF should not be. With additional prevention research into oxygen dosages²² and the mechanisms by which oxygen "poisons" the eye, better techniques of monitoring oxygen administered to infants, better incubators, and improved understanding by physicians (especially pediatricians and obstetricians), the disease is probably about 95 percent or more preventable. The remaining 5 percent would occur in those stark and critical situations where blindness may reluctantly be chosen as the lesser undesirable outcome in a life-threatening situation. Better prenatal care, to cite a more general prevention strategy, could furthermore lessen the prevalence of prematurity (a proven relationship exists between prenatal care and the likelihood of a premature birth) and hence the need for oxygen therapy.

A number of disorders can be corrected or contained and need not cause handicaps; however, success in nearly all of these depends on the earliest possible identification (before the age of 5 in most cases) and correct medical treatment.

Several disorders are detectable with *in utero* assessment techniques, even at the relatively underdeveloped state of the practice,²³ but the degree of preventive potential depends on the accessibility of an up-to-date identification and preventive care program, genetic counseling, and the choice by parents on whether or not to terminate the pregnancy when a major handicapping disorder is actually detected.

PREVENTION STRATEGIES

We now turn to the question of strategies for prevention, and discuss prenatal care; immunization; timely identification, direction and proper medical treatment; family planning; genetic counseling; and abortion and other practices.

Prevention Tradeoffs

In deciding whether to implement any of the prevention strategies to be described, or in deciding on modification of existing prevention programs, one must confront the question of the tradeoff between current costs of a prevention program, future costs in terms of the reduced quality of life of persons whose handicaps are

²² Just such a program, albeit a very modest one, is currently under way in the Medical School at The Johns Hopkins University.

²³ No one has devised a safe technique for sampling fetal blood, but when it is discovered, an assortment of genetically related disorders will become candidates for prevention if parents choose to have an abortion.

not prevented, and future costs of service to those persons. While the logic is clear, it is extremely difficult to make a tradeoff in practice. Not only are data lacking, but dollar estimates attached to decreases in quality of life are bound to be somewhat arbitrary. For example, suppose one desires to determine the level of preventive activity that results in a minimum total of prevention costs plus "disamenity" costs associated with reduced quality of life and with later service needs due to handicaps not prevented. For illustration, a simplistic version of the problem is presented in Fig. 6.1, which plots hypothetical costs of prevention, "disamenity" costs of handicaps not prevented, and total costs.²⁴

The purpose of a mathematical analysis of data plotted in such a figure could be to assess relative prevention strategies to determine how far a strategy could be used before the returns become marginally disadvantageous—i.e., the cost of one more prevention exceeds the "disamenity" cost of not preventing one more handicap. To perform this type of analysis, data must be available for each prevention strategy and each disorder, and one must be able to arrive at a way of expressing quality of life in money or commensurate terms.

In practice, the type of analysis implicit in Fig. 6.1 has little direct relevance.²⁵ The available data make it difficult enough to account with any accuracy for all factors contributing to prevention costs, e.g., research, training, operations; and no one can reliably estimate the costs or benefits of as yet unrealized technological breakthroughs as they may contribute to an improved prevention service. Data to provide a clear understanding of factors causing a specific disorder, and the contributions of a given preventive strategy to reduced prevalence and to reduced future service cost, are not fully available either. And finally, this style of analysis necessarily overlooks some difficult but important problems, including the "cost" and "worth" of human life, individual variations in preferences, thresholds of pain or suffering, and other bearable or perhaps unbearable costs of "disamenity."

What is left to us, then, to help decide whether increased prevention activity is desirable? For the Vocational Rehabilitation program, where data are relatively good, we are able to perform a fairly sophisticated benefit-cost analysis (see Chapter 9); the basic point made there is that program-costs to society, to the taxpayers, and to the handicapped individual are all less than the program's corresponding future economic benefits; and increased quality of life adds even more benefits. We use a similar line of argument, for example, in a rubella immunization program analysis made later in this section. We show that the costs of the rubella prevention program are far less than the future discounted incremental costs of special education for persons whose handicaps the program could have prevented. (And added quality-of-life benefits and reduced future costs of other services would justify this program still further.)

Another approach is to consider the service costs for hearing and vision handicapped children, asking how expensive a prevention program can be and still fall below the service costs for handicaps not prevented. For example, assume that the present annual government expenditure of \$420 million²⁶ for services for the 683,-

²⁴ A related discussion is contained in Charles D. Scott, "Health Care Delivery and Advanced Technology," *Science*, Vol. 180, June 29, 1973, pp. 1339-1342. The topic has also been treated in D. P. Rice, *Estimating the Costs of Illness*, Public Health Service, Publication No. 947-6, Washington, D.C., 1966; and Chauncey Starr, "Social Benefit Versus Technological Risks," *Science*, Vol. 165, 1969, p. 1232.

²⁵ We are not saying that conducting such analyses is not without value; rather, we are facing the immediate practicality issue. An otherwise elegant and thorough analysis ran into difficulty on precisely this point: see S. Fanshel and J. W. Bush, "A Health-Status Index and Its Application to Health-Services Outcomes," *Operations Research*, Vol. 18, No. 6, November-December 1970, pp. 1021-1066. This article contains an excellent bibliography describing the state of the field.

²⁶ Rand Report R-1220-HEW, Chapter 2.

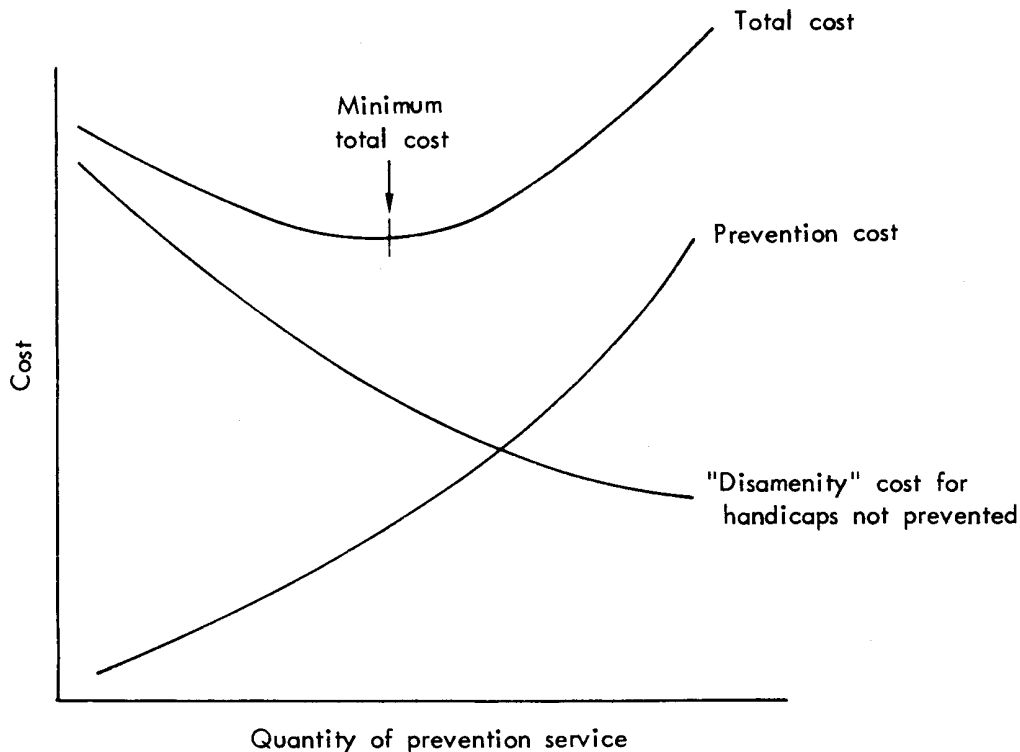


Fig. 6.1—Hypothetical prevention cost relationships

000 hearing and vision handicapped youth, or \$615 per handicapped youth, is representative of the average annual incremental cost for the handicap to be prevented by a proposed program.²⁷ The present value of 21 years of expenditures for the handicapped youth is approximately \$6150 at an 8 percent discount rate. In this example, the prevention program would be justified, on grounds of reduced future service costs alone, if the prevention cost per handicap prevented is less than about \$6150. If one further assumes, not unreasonably, that the humanitarian quality-of-life benefits of not being handicapped are worth at least ten times this reduced service cost, then the program would be justified on humanitarian grounds alone if the prevention cost is less than about \$60,000 per handicap prevented. In other words, the program would be justified on humanitarian grounds if costs are \$60 per youth and only 1 in 1000 youth receiving the service had a handicap prevented as a result (or \$6 and 1 in 10,000, or \$600 and 1 in 100).

We now turn to a summarization of individual types of prevention strategies.

²⁷ The \$615 figure is not the true value of the incremental cost, of course, but it is probably of the correct order of magnitude. Estimation of the actual incremental cost is considerably more complex; it involves such factors as determining what amount of current expenditures would not be reduced, such as a portion of Medicaid for families that might be needy even without a handicapped child, and such as various program "overhead" costs; and predicting what would be the particular government program organizational reactions to a smaller handicapped population, such as more outreach to find clients, or providing a higher level of service to individual clients. It would also be necessary to estimate the incremental cost savings and increased benefits for the particular mix of types and degrees of handicaps to be prevented, and from the viewpoint of particular program objectives.

Prenatal Care as a Prevention Strategy

Partly because of the leadership along a broad research front provided by the National Institute of Child Health and Human Development,²⁸ more is being learned about the critical importance of prenatal care as a general preventive strategy. Specific relationships between a number of prenatal conditions and subsequent sensory disorders are known; and many other suspected conditions, given the prevalence of "unknown prenatal influence" as an etiologic class for sensory handicaps, have become fitting research topics.

In an informative summary of "dos and don'ts" for a pregnant woman, Jane Brody²⁹ has made the following observations—all of which contribute generally to reduced chances of producing an abnormal baby.

- Most important is the early and periodic prenatal examination by a competent physician. All adverse indicators, e.g., low birth weight, prevalence of defects, fetal misadventure, are positively related to poor or non-existent prenatal care.
- Drug intake, including common non-prescription, prescription, and "dangerous" drugs should be sharply curtailed or eliminated altogether. If drugs must be taken, it should be done *only* with the guidance and prescription of a physician, preferably the obstetrician responsible for the prenatal course of treatment. In this regard, no drug—no matter how "harmless"—is to be considered above reproach. Definitive research has just not been done in sufficient quantity to rule out the potentially damaging effects of *any* drug or foreign chemical substance, and this includes aspirin, nicotine, caffeine, and vitamins taken in excessive amounts, as well as prescription medications, e.g., steroids, progesterone, antibiotics, diuretics, antihistaminics, anti-depressants.³⁰
- Proper nutrition is important as a part of sound prenatal care; protein deficiencies, for instance, are known to be related to decreased cerebral development.³¹
- Abdominal x-rays should be avoided, especially in the first weeks of pregnancy.
- Live virus vaccines should not be administered if pregnancy is suspected; included on this list are small pox, measles, rubella, mumps, and yellow fever.

Good general prenatal care will also detect syphilis in routine serologic work-ups. Congenital syphilis is apparently on the increase, and has been suspected in congenital sensorineural hearing loss, keratitis, and cataract.

The relationship between prenatal drug intake and subsequent hearing loss in the infant has been established for antibiotics in the mycin group, is suspected with other antibiotics, and is known to exist in the case of quinine. Various hearing disorders linked to drug intake include congenital malformations of the Organ of Corti and irreversible damage to the auditory nerve. Congenital cataract and drug intake are suspected to be related. The general caution noted for prenatal drug use pertains.

X-rays in the early stages of pregnancy are suspected in cases of congenital cataracts and other malformations of the eye.

Finally, vaccination of a pregnant female against mumps, rubella, and measles with a live virus vaccine is capable of infecting and causing harm to the fetal sensory organs.

²⁸ Rand Report R-1220-HEW, Chapter 9 contains a program summary for NICHD.

²⁹ *How a Mother Affects Her Unborn Baby*, National Institute of Child Health and Human Development, Washington, D.C., 1971 (reprint).

³⁰ NICHD supports a modest program in Prenatal Pharmacology that addresses many of these issues.

³¹ See also *Nutrition and Human Development: A Special Report Prepared for the National Advisory Child Health and Human Development Council*, NICHD, Washington, D.C., November 17, 1969.

Immunization

A major strategy for prevention of sensory handicaps is to immunize to prevent diseases and disorders that can cause handicapping, such as measles, mumps, and especially rubella and Rh sensitivity. While the probability of handicapping from measles and mumps is relatively low, there is great danger with Rh sensitivity and rubella (especially if a woman contracts it during the first trimester of her pregnancy). And, as we will illustrate for rubella, the cost of an immunization program can be low compared with the costs of handicapping.

A problem is that many persons are not receiving this obvious type of prevention service. For example, recent reports from the National Center for Disease Control in Atlanta have registered concern that not enough children in rural and central city areas are being vaccinated against polio and measles. Especially significant was the finding that about one-half of central city children surveyed were *not* protected against measles or polio. More than 75,000 cases of measles were reported in 1971, an increase of 28,000 over the previous year.³² It is a persistent problem, reflecting both the fragmented nature of the health system generally and the particularly limited interest given to preventive activities as contrasted with most other services.³³ It apparently takes an epidemic to force preventive immunization into the forefront.

No one government agency is primarily responsible for coordinating immunization programs (including research, assuring production and quality of the vaccine or serum, delivery of the service, and then evaluation of program effectiveness). And government costs for immunization are not born by the same agencies that reap future benefits—these benefits being “successful” prevention, cases of diseases that did *not* occur and did *not* cause handicapping, and hence service costs that were *not* incurred later.

While the National Center for Disease Control has been a leader in promoting immunization programs, implementation has been delegated to state and local health authorities, who are left for the most part to their own devices. The results have been mixed, as documented in the recent rubella evaluation study conducted for the Office of the Secretary, Department of Health, Education, and Welfare by Bio-Dynamics, Inc.³⁴

Rubella. It took a major epidemic in the early 1960s to galvanize official attention in the case of rubella, but in the absence of subsequent catastrophes, maintenance of this attention and activity has waned. Specific details of what this entails for the rubella prevention program include the following:

- There is marked unevenness in the quality of community-run programs and slight provision available to correct the more deficient ones.
- Identification of people in at-risk groups is not uniformly well done, with the result that coverage is uneven.

³² See *Education Daily*, May 5, 1972, p. 6, which also notes that both measles and diphtheria have risen sharply since 1970, a finding alleged to be linked to certain federal government officials’ “reluctance to support special vaccination programs,” whereby preventive activities have been “lumped into a generalized program which gives local and state governments freedom to choose how the money will be spent.”

³³ Former Secretary of Health, Education and Welfare Abraham Ribicoff is quoted as saying, nine years ago, that the vaccination programs existing then had two major weaknesses: “First, they have been so closely related to school admissions that they have provided poor coverage for preschool children. Second, they have been least effective in reaching families in low-income neighborhoods.” *Proceedings, 2d Annual Immunization Conference*, May 1965, p. 5, as cited in Bio-Dynamics, Inc., *Evaluation of the Rubella Immunization Program*, Department of Health, Education and Welfare, Office of the Assistant Secretary for the Planning and Evaluation, Contract No. HEW-OS-70-153, Washington, D.C., 1972, p. 8.

³⁴ Bio-Dynamics, Inc., *op. cit.*, pp. 75-81.

- School-based programs miss many preschoolers.
- Maintenance and surveillance are crudely developed and “the probability of satisfactory maintenance after federal funding ends is poor.”
- Private physicians are not included in the reporting procedures of the program; program effectiveness studies are thereby biased.
- The Center for Disease Control needs considerable strengthening to carry out its responsibilities.

And finally, the most significant finding of all:

At this time there is substantial evidence that seven years of the Vaccination Assistance Act did not provide all states with the means to continue high levels of immunization. The Federal grants mechanism did not provide adequate incentive to build this at the local level nor the technical assistance to show how it can be done. The established public health structure demonstrated capability to carry out the attack phase but not the maintenance phase.³⁵

The importance of long-term maintenance of preventive activities may be stressed in a simple cost exercise designed to relate prevention costs to service costs for handicaps resulting from inadequate prevention.

The rubella epidemic of 1963-1965 left an estimated 20,000 to 30,000 handicapped children in its wake, a tragedy that society will be paying for in many significant ways for years to come.³⁶ In his analysis, Donald Calvert estimated the special educational costs alone associated with the impaired subset of the epidemic population.³⁷ We have made our own more conservative estimates based on special education expenditure data presented in Chapter 8 of this report for the *discounted incremental costs* above the cost of regular education. Further, we have omitted educational costs for what Calvert has termed “mild to moderate” handicaps, biasing our special education cost figures down even more. As can be seen in Table 6.3 Calvert’s and our estimated special educational costs differ significantly; however, even taking our intentionally conservative estimate as a basis of comparison, there is a striking difference between the \$202 million increased special educational costs due to that one rubella epidemic and the \$41.6 million total authorized under the Rubella Immunization Program.³⁸ And we have not even considered increased costs of services other than special education in the calculation, not to mention the degradation of quality of life inflicted by the handicaps.

The urgency of such preventive programs is manifest if we look only at the high annual cost associated with the special education of deaf-blind children: from \$12,000 to \$14,000 per child.³⁹ For the estimated 1250 deaf-blind children resulting from the 1963-1965 rubella epidemic, this represents an annual outlay of \$15 million (using the low estimate)—but in 1972 only \$7.5 million was expended for establish-

³⁵ Ibid., pp. 6-9.

³⁶ J. L. Sever et al., “Epidemiological Observations of Rubella in the Collaborative Perinatal Research Study,” *Proceedings, International Conference on Rubella Immunization*, Stockholm, Sweden, February 18-20, 1969.

³⁷ Donald R. Calvert, *Report on Rubella and Handicapped Children*, Department of Health, Education and Welfare, Bureau of Education for the Handicapped, Washington, D.C., May 1969.

³⁸ Section 314(e) of P.L. 89-749.

³⁹ The low estimate is that used by California’s School for the Blind in their Deaf-Blind program, and the high figure is that reported by Calvert for Massachusetts’ Perkins School for the Blind’s program in 1969.

Table 6.3

ESTIMATED COSTS FOR 13 YEARS OF SPECIAL EDUCATION OF HANDICAPPED CHILDREN RESULTING FROM THE RUBELLA EPIDEMIC OF 1963-1965

Handicap	Number	Undiscounted	Discounted
		Total Cost: Calvert Estimate	Total Incremental Cost: Rand Estimate
Visually impaired	5,500	\$250,250,000	\$ 35,500,000
Hearing impaired	12,000	468,000,000	77,400,000
Deaf-blind	1,250	227,500,000	81,000,000
Retarded/crippled	1,250	48,750,000	8,100,000
Total	20,000	\$994,500,000	\$202,000,000

SOURCE: Donald R. Calvert, *Report on Rubella and Handicapped Children*, Department of Health, Education and Welfare, Bureau of Education for the Handicapped, Washington, D.C., May 1969.

NOTE: Rand estimates are based on expenditure data in Chapter 8 of this report. Thirteen-year costs are discounted at 8 percent to time of birth.

ing and supporting Deaf-Blind Centers for *all* of the 4728 identified deaf-blind children in the United States as of January 1, 1972.⁴⁰

The messages from this example and discussion are clear:

- Rubella can be prevented.
- Rubella-caused handicaps are expensive.
- Prevention is decidedly cost-effective.

But,

- Attention to the rubella immunization program is flagging, with potentially tragic and costly results.

It would be easy to conclude summarily with the recommendation that renewed vigilance be applied to rubella immunization efforts; but several confounding facts must be taken into consideration before making such an appeal.

There is evidence that rubella may have been controlled as a result of the mass immunization program. The Center for Disease Control noted only 21,424 cases of rubella in the first 39 weeks of 1972, a 44 percent decline over a comparable period in 1971.⁴¹ While the trend has been downward since the 1969 initiation of rubella immunization efforts, one must caution that rubella occurs periodically, normally in a 6 to 9 year cycle, and 1972 would have been at the leading edge of the normal period. Control of the disease is not accomplished "once and for all," and eradication is probably out of the question given its worldwide prevalence.

There is also evidence that the "herd immunity" approach adopted in the original rubella program does not work as well as it was expected to.⁴² For instance,

⁴⁰ U.S. Congress, House, Subcommittee of the Committee on Appropriations, *Hearings, Part 2, Office of Education and Special Institutions*, 92d Cong., 2d sess., 1972 (hereafter cited as *Hearings*), p. 403.

⁴¹ Reported in *Education Daily*, Vol. 5, December 20, 1972, pp. 1-2. Estimates vary, but somewhere between 30 and 40 million children have been immunized in the program.

⁴² J. P. Fox et al., "Herd Immunity: Basic Concept and Relevance to Public Health Immunization Practices," *American Journal of Epidemiology*, Vol. 94, 1971, pp. 179-189. The concept is that, if a sufficiently large fraction of the population is immune, transmission of the disease is inhibited and the potential for an epidemic reduced.

Klock and Rachelefsky, in reporting on an epidemic localized to Casper, Wyoming in early 1971,⁴³ found that while 83 percent of the elementary school and 52 percent of the preschool population had been immunized (and for these groups protection was excellent), older youth had not been immunized while young, and some 1,000 cases of rubella occurred in a population of some 40,000. Eighty-four percent of those afflicted were teenagers, and 27 cases occurred in women, 7 of whom were pregnant. While others have used these findings to argue for the repeal of some 22 state laws mandating rubella immunization as a requirement for school admission, the following are the conclusions drawn by the investigators from the Casper case:

Although the vaccination of prepubertal children in Casper did not prevent an epidemic, this effort undoubtedly did prevent infection of a number of pregnant women after the epidemic began. If younger children had not been immunized, the outbreak would have been more extensive, and the number of exposed, susceptible women would have been much higher. Thus, childhood rubella immunization remains an important method of rubella prevention; however, because of the potential for outbreaks in older children this procedure should be supplemented by other methods of rubella control. The most important of these is the identification and vaccination of susceptible, nonpregnant women in the child-bearing age.⁴⁴

Other specialized literature on the rubella immunization issue generally supports these findings and conclusions.⁴⁵ Among other partial results contained in this body of literature, the following summary points stand out.

- As contrasted with selective vaccination programs directed at the at-risk population of women of child-bearing age, the herd immunity concept does not appear to be completely reliable.
- More than 95 percent of those vaccinated develop serum antibodies and appear in the short term to demonstrate protection. (Reinfection rates among naturally immunized and vaccinated populations have not been established but should be given careful surveillance.)⁴⁶
- The chances of a previously immunized female becoming reinfected and if reinfected, transmitting the disease to the fetus, are not known.⁴⁷
- It is known that the vaccination is capable of producing unpleasant side effects, both in children and particularly in postpubescent females.⁴⁸

⁴³ Lawrence E. Klock and Gary S. Rachelefsky, "Failure of Rubella Herd Immunity During an Epidemic," *New England Journal of Medicine*, January 11, 1973, pp. 69-72.

⁴⁴ *Ibid.*, p. 72.

⁴⁵ National Center for Disease Control, "Rubella Virus Vaccine: Recommendation of the Public Health Service Advisory Committee on Immunization Practices," *Annals of Internal Medicine*, Vol. 75, 1971, pp. 757-759; D. M. Horstman, "Rubella and the Rubella Syndrome: New Epidemiologic Virologic Observations," *California Medicine*, Vol. 102, 1965, pp. 397-401; S. A. Plotkin, "Virologic Assistance in the Management of German Measles in Pregnancy," *Journal of the American Medical Association*, Vol. 109, 1964, pp. 105-108; J. J. Witte et al., "Epidemiology of Rubella," *American Journal of Disabled Children*, Vol. 118, 1969, pp. 107-111; S. A. Wyll and M. G. Grand, "Rubella in Adolescents: Serologic Assessments of Immunity Levels," *Journal of the American Medical Association*, Vol. 220, 1972, pp. 1573-1575; H. M. Meyer, Jr., and P. D. Parkman, "Rubella Vaccination: A Review of Practical Experience," *Journal of the American Medical Association*, Vol. 215, 1971, pp. 613-619; A. D. Heggie and F. C. Robbins, "Natural Rubella Acquired after Birth," *American Journal of Disabled Children*, Vol. 118, 1969, pp. 12-17; and R. H. Green et al., "Rubella: Studies in its Etiology, Epidemiology, Clinical Course, and Prevention," *Transactions of the Association of American Physicians*, Vol. 77, 1964, pp. 420-427.

⁴⁶ D. M. Horstman et al., "Rubella: Reinfection of Vaccinated and Naturally Immune Persons Exposed in an Epidemic," *New England Journal of Medicine*, October 1970, pp. 771-778.

⁴⁷ Plotkin, *op. cit.*, pp. 105-107.

⁴⁸ L. Z. Cooper et al., "Rubella: Clinical Manifestations and Management," *American Journal of Disabled Children*, Vol. 118, 1969, pp. 18-29.

A conservative recommendation, based on these findings, has been offered by Vincent Fulginiti, a virologist, in the following terms:

The author feels there is sufficient uncertainty about the effectiveness of mass rubella immunization, sufficient question concerning pharyngeal virus growth in the vaccinee, and sufficient doubt about the significance of side-effects to question the wisdom of utilizing rubella vaccine routinely in childhood. A preferable alternative at present would be to immunize all pre-pubescent females, to test all women in the child-bearing age group for rubella antibody, and to immunize those who are susceptible (approximately 15%). It is necessary to make absolutely certain that pregnancy is avoided for at least 2 months following such immunization.⁴⁹

However, this recommendation is somewhat at odds with a recent Public Health Service Advisory Committee opinion that all children between the age of 1 year and puberty should receive a rubella vaccination.⁵⁰

A basis for reconciliation of the views is contained in our following recommendations for an improved rubella immunization program.

- Mandate vaccination for all pre-pubescent females through a school-based program conducted under the auspices of the National Center for Disease Control.
- Create a model code for state marriage license serologic screening practices with the objective of including an additional test for the presence of rubella antibodies.
- Conduct an appeal through the mass media and professional medical publications to encourage all childbearing females to obtain such tests from their private physicians. The decision to proceed with vaccination, in the estimated 15 percent thought not to be naturally immune, then becomes a uniquely determined one between doctor and patient.
- Conduct periodic studies of reinfection rates among vaccinated and naturally immunized populations to determine whether the efficacy of the initial, massive rubella immunization program is sustaining or not.

The first recommendation represents a reduced but more tightly focused extension of the national rubella immunization program. With continuous application, all of the at-risk population will be protected in the long term. Prepubescent restrictions for administration of the vaccine minimize the danger of arthritic complications and not selecting male children confronts the breakdown in herd immunity noted by Klock and Rachelefsky; for males, contracting the disease may present fewer and less severe risks than possible complications of adverse reactions to the vaccine.

Given that on the order of 4 million live births per year were recorded in the decade between 1960 and 1970,⁵¹ about 2 million vaccinations per year would be needed to reach the entire at-risk population on an annual cohort basis. At current costs of \$0.47 per dose,⁵² total vaccine costs would be around \$1 million per year in the long run. Even at \$5.00 per dose, the costs of \$10 million per year would be small relative to savings in later service costs for handicaps not prevented.

The second recommendation is more an identification plus prevention service than it is a purely preventive one. Blood tests for syphilis are required in most states

⁴⁹ Vincent A. Fulginiti, "Immunization," in C. Henry Kempe et al., *Current Pediatric Diagnosis and Treatment*, Lange Medical Publications, Los Altos, Calif., 1972, pp. 107-122, at pp. 117-118.

⁵⁰ National Center for Disease Control, "Rubella Virus Vaccine: Recommendation. . ."

⁵¹ U.S. Bureau of the Census, *Statistical Abstract of the United States 1972*, Washington, D.C., p. 50.

⁵² Bio-Dynamics, Inc., op. cit., p. 39.

already, and the test for rubella antibodies is rather easily and inexpensively done at the same time. Provision to test women for the rubella antibodies has been enacted into law in California in the form of Senate Bill 1002, approved in August 1972.⁵³ Briefly, the law requires, with several exceptions, a physician's certification that in addition to being free from syphilis, all female marriage license applicants have been tested for an immunological response to rubella. Nothing beyond informing the woman is contained in the law, but presumably positive identification could result in advice to consult a private physician about the possibility of obtaining a vaccination.⁵⁴ The law itself represents a "natural" social experiment involving a state with 10 percent of the nation's population, and deserves to be evaluated as such, to assist other states considering following suit with versions of the same legal provision. The possible damage in an unsuspected pregnancy by administration of the rubella vaccine is known to be great. It is also known that the virus is often long-lived, which means that any childbearing female *should not* become pregnant for *at least* two months after receiving the vaccine.

Our third recommendation stresses the private physician's role, as opposed to a direct governmental one, in reaching childbearing women who are either unmarried or already married and hence would be missed in a screening of marriage-license applicants.

The issue of reinfection rates is not settled, but warrants careful surveillance. The rubella vaccine has been in widespread use in the United States less than five years, certainly insufficient time to establish its long-term persistence with great reliability.

Rh Sensitivity Immunization. Development and use of the Rh desensitizing gamma globulin has resulted in a reduction of newborn jaundice, and with it a reduction in the associated hearing disorder erythroblastosis fetalis. However, the RhoGAM must be administered within 72 hours after the Rh-negative mother has terminated pregnancy of an Rh-positive child to prevent sensitization and subsequent threat to children born later. Blood-typing and antibody screening are considered an important part of effective prenatal care, and based on the bilirubin levels obtained in amniocentesis (when indicated), specific management procedures for mother and unborn child may be required.⁵⁵ Immunization, typing, screening, evaluation, and management are all elements of responsible preventive care. The extent of reduction in handicapping resulting from having this kind of care widely available is not known, but is clearly significant.

Routine Immunization. Modern standards of pediatric practice call for a routinized immunization program such as the representative schedule approved by the Committee on Infectious Diseases of the American Academy of Pediatrics (Table 6.4). Exact timing and sequencing are matters left to the physician's discretion.

Following such a schedule increases protection against a number of formerly devastating diseases. Of the group, measles, mumps, and rubella have all been

⁵³ *Deering's Code of Civil Procedure*, Vol. I, Pamphlet No. 5, 1972, Chapter 714, pp. 22-23; and *Civil Code of the State of California*, Sections 4300 and 4302, as amended by S.B. 1002, 1972. Implementation was delayed until January 1, 1974.

⁵⁴ The California blood test law also contains a reference to possible use of the serologic specimen for identification of "carriers of genetic diseases, including, but not limited to, sickle cell anemia and Tay-Sachs disease, and that such tests may be performed at the same time as those tests required in Section 4300." *Deering's Code*, p. 23. The implications of this law are potentially far-reaching, a point discussed in a following section on "Genetic Counseling."

⁵⁵ A. G. Charles and E. A. Friedman, *Rh Isoimmunization and Erythroblastosis Fetalis*, Appleton-Century-Crofts, New York, 1969; and J. T. Queenan, *Modern Management of the Rh Problem*, Harper Medical Division, Hagerstown, Md., 1967.

Table 6.4

REPRESENTATIVE IMMUNIZATION SCHEDULE

Age	Immunization
2 months	1. Diphtheria, tetanus (toxoids), and pertussis (antigen) combination injection (DTP) 2. Trivalent oral polio vaccine (TVOP)
4 months	1. DTP 2. TVOP
6 months	1. DTP 2. TVOP
1 year	1. Measles 2. Tuberculin test
1 to 12 years	1. Rubella vaccine ^a 2. Mumps vaccine
1½ years	1. DTP 2. TVOP
4 to 6 years	1. DTP 2. TVOP
14 to 16 years	1. Tetanus and diphtheria toxoids (adult form). At this age and every ten years thereafter.

SOURCE: Committee on Infectious Diseases of American Academy of Pediatrics, as summarized in C. Henry Kempe et al., *Current Pediatric Diagnosis and Treatment*, Lange Medical Publications, Los Altos, California, 1972 ed., p. 111.

^aSee comments in above section on rubella.

implicated in sensory handicapping, and faithful adherence to a basic immunization program should ensure prevention at a relatively high level.

However, as noted earlier in this chapter, evidence indicates that general and proper adherence to such a schedule is not always forthcoming, especially for rural and central-city children. The long-term benefits achievable under preventive programs, such as those contained in the Vaccination Assistance Act of 1962 and recent extensions and amendments to that act, should not be forgone in the interests of short-term economies. Public Law 91-464 in particular has some creative and interesting possibilities for comprehensive and significant prevention of many sensory handicaps, e.g., those associated with rubella, measles, venereal disease, mumps, and Rh Sensitivity, among others.⁵⁶

Identification, Direction, and Medical Treatment

Previous chapters have stressed the need for early identification, appropriate direction to servers with requisite skills, and skillful medical treatment of the underlying disorder. Details of those discussions will not be repeated here; however, adequate provision of these services has a distinct preventive component.

While one cannot precisely estimate the reductions in handicapping that improvements in these services bring about, the effects are certainly positive. In principle, such improvements could reduce the handicaps attributable to the *majority* of the different types of sensory disorders. From a preventive viewpoint, the problem

⁵⁶ P.L. 91-464, 91st Congress, S.2264, October 16, 1970.

is not inadequacy of technical knowledge and skill, but a problem of promptly identifying children in need and putting them in touch with the considerable medical-technical expertise that already exists. To the extent that society can solve that problem, a remarkable number of lifelong sensory disorders are, in the strictest sense of the word, *preventable*.

To realize some of these benefits, we urge the adoption of all previous recommendations made with respect to identification, direction, and medical treatment services (Chapters 3, 4, and 5).

Early and correct identification of potentially handicapping conditions is perhaps the single most important and underrated service in the array of potential prevention strategies. It is the keystone in a truly comprehensive and effective program for the handicapped. Early identification also has a distinct, but ill-appreciated, preventive component: it increases the likelihood that cause and outcome will be known and properly associated, and that early warning will be given of changes in causes of handicapping in the total population. The implications for improved prevention research and operations are clear.

A related prevention strategy is to avoid providing types of medical treatment that can cause or exacerbate handicaps. We have already discussed two types of treatment to be either avoided when possible or judiciously used otherwise: administration of ototoxic drugs, such as quinine and certain antibiotics in the mycin group, possibly resulting in damage to the auditory nerve; and administration of excessive oxygen to premature infants, possibly resulting in retrolental fibroplasia (see Chapter 5).

Family Planning

Family planning is another general preventive strategy that can reduce handicapping. While relationships between the likelihood of mental impairment in the infant, the age of the mother, and the total number of children produced have been established (Table 6.5), similar demographic analyses have not been carried out for the sensorially handicapped, as far as we can determine. One may only surmise that family planning practices, such as having only two children and only at maternal ages between 20 and 34, could have some positive, but inestimable, effect on the prevalence of sensory handicaps in the overall population.

Table 6.5

RELATIONSHIP BETWEEN MENTAL DEFICIENCY AND
MATERNAL AND FETAL FACTORS

Birth Order	Ratio of Observed to Expected (percent)	Maternal Age	Ratio of Observed to Expected (percent)
1	52	Under 20	121
2	92	20-24	95
3	135	25-29	88
4	145	30-34	95
5	268	35 and over	146

SOURCE: *American Journal of Mental Deficiency*,
Vol. 60, January 1956, pp. 557-569.

Genetic Counseling

Hereditary factors are known to be important determinants of the number of hearing and vision handicapped children in the total population. Chung and his associates have estimated, for example, that about half the cases of profound hearing impairment can be traced to genetic origins.⁵⁷ And over one-half of the cases added to the Model Reporting Area "legal blindness" registers in 1969 and 1970 for youth aged 19 and under were listed as owing to "prenatal influence," indicating the hereditary importance of many visual disorders.⁵⁸ Some 50 defined syndromes have been associated with hereditary hearing loss,⁵⁹ and numerous visual disorders are similarly characterizable.⁶⁰

Such factors generally indicate that more attention should be given to genetic screening and research into the hereditary hearing and vision handicaps. The establishment of an accurate genetic diagnosis, according to W. E. Nance,

is a prerequisite for rational counseling, which in turn can prevent the tragedy of a second affected child. Because of the extensive heterogeneity that exists among the various types of hereditary deafness, the risk of affected children for deaf couples is often quite low, but again, reliable prediction depends upon an accurate diagnosis. Specific remediation is possible for some forms of hereditary deafness, and future research will undoubtedly bring to light new types for which effective treatment and even prevention or cure is possible.⁶¹

While the future trend may include increased genetic counseling, including the taking of blood and tissue cultures for chromosome morphology, many significant difficulties must first be surmounted before this form of preventive service can realize its potential in widespread use.⁶²

Experience with a national genetic screening program to detect sickle cell anemia, perhaps the largest-scale genetic screening and counseling program in existence, has shown that the underlying intentions of those running the program are not necessarily shared by those being screened and that the unanticipated, and frequently negative, consequences of the program bear some serious consideration.⁶³

- Mass screening has indicated that the issues related to public education, community relations, and the private lives of the identified trait-carriers are in need of resolution.
- The identified individual's reactions are not always positive and favorable.
- Community resistance is more common and far greater than any of those responsible for the program had expected.

⁵⁷ C. S. Chung, O. W. Robison, and N. E. Morton, "A Note on Deaf Mutism," *Annals of Human Genetics*, Vol. 23, 1969, pp. 357-366.

⁵⁸ Harold A. Kahn and Helen B. Moorhead, *Statistics on Blindness in the Model Reporting Area, 1969-1970*, National Eye Institute, DEW Publication (NIH) 73-427, Washington, D.C., 1973, p. 75, Table 17d.

⁵⁹ B. W. Konigsmark, "Hereditary Deafness in Man," *New England Journal of Medicine*, Vol. 281, 1969, pp. 713-720, 774-778, 827-832.

⁶⁰ See Chapter 5 of this report.

⁶¹ W. E. Nance, "Genetic Counseling for the Hearing Impaired," *Audiology*, Vol. 10, 1971, pp. 222-233, at p. 223.

⁶² The current *International Directory, Genetic Services*, The National Foundation-March of Dimes, White Plains, New York, 1971 ed., lists some 680 genetic service units throughout the United States and Canada. This represents a fourfold increase in five years.

⁶³ Barbara J. Culliton, "Sickle Cell Anemia: National Program Raises Problems as Well as Hopes," *Science*, Vol. 178, October 20, 1972, pp. 283-286.

- There is a real danger that those identified as carrying the trait will suffer from the stigma associated with that finding. (See Chapter 4 on problems of identification.)
- The eugenic implications of the entire program loom large and are far from being resolved.

Other reports on genetic screening programs have similar messages. For example, Leonard and associates report that for a study sample of parents having had children with cystic fibrosis, phenylketonuria, and Down's Syndrome, only about one-half had "a good grasp of the information given, 1/4 gained something, and 1/4 learned very little,"⁶⁴ as a result of genetic counseling. The problem appeared, in this case, to be related to the skills of the physicians who participated in the counseling program, among other reasons. The information level attained by parents is critical in determining whether and how such knowledge will be used in making decisions about having additional children. Exacerbating the decisionmaking process are religious concerns, emotional conflicts between the parents, and a general lack of understanding of genetics and the probabilities associated with subsequently producing handicapped offspring.

The general issue of genetic screening and counseling represents a clear instance of technology's having outpaced society's ability to use, accept, and cope with the technology. Many persons, fortunately, are becoming concerned with some of these implications, although the day when effective, widespread prevention of handicapping through genetic screening and counseling practices overtakes us still seems remote. Ethical, societal, and practical political questions are at least discernible.

On the ethical and social dimensions, a distinguished group under the leadership of Marc Lappé, of the Institute of Society, Ethics, and the Life Sciences has mapped the roughest contours of the hazardous terrain confronting society in the general area of genetic screening.⁶⁵ Among the many thorny issues raised in this report, the following appear especially salient with respect to the longer term prospects for preventive practice.

- Does information obtained by genetic screening fall outside the normal confidentiality provisions enjoyed in the traditional doctor-patient relationship?
- What is the relationship between adverse genetic information and the remedial actions implied in such information? This issue is at the heart of the unresolved debate on the legality and morality of abortion, among other things.
- What are the deep scientific *and* human implications of programmatic objectives of any genetic program?
- How can the quality of test and screening instruments be assured to avoid the multiple pitfalls and human costs associated with misidentification?
- What compulsive measures are implied in the true positive identification of a parent pair likely to produce "defective" offspring? The Lappé group states unequivocally: "As a general principle, we strongly urge that no screening program have policies that would in any way impose constraints on childbearing by individuals of any special genetic constitution, or would stigmatize couples

⁶⁴ Claire O. Leonard, Gary A. Chase, and Barton Childs, "Genetic Counseling: A Consumer's View," *The New England Journal of Medicine*, Vol. 287, No. 9, August 31, 1972, pp. 433-439, at p. 433.

⁶⁵ Marc Lappé et al., "Ethical and Social Issues in Screening for Genetic Disease: A Report from the Research Group on Ethical, Social and Legal Issues in Genetic Counseling and Genetic Engineering of the Institute of Society, Ethics, and the Life Sciences," *New England Journal of Medicine*, Vol. 286, May 25, 1972, pp. 1129-1132.

who, with full knowledge of the genetic risks, still desire children of their own."⁶⁶

- What provisions can be adopted to insure informed consent of the participants in any screening program?
- How can participants be adequately apprised of the risks involved in possible psychic and social injury?
- Should the purposes and objectives of the screening program be made publicly available?
- Have competent counseling provisions been developed in advance of the screening activity to provide follow-up information and service to those thought to have a potential for parenting genetically handicapped offspring?
- How can rights of privacy be insured?

The general tone of the report and the guidelines promulgated is one of cautioning about the extreme potential risks and costs involved in a genetic screening program.

We are concerned about the dangers of societal misinterpretation of similar conditions and the possibility of widespread and undesirable labeling of individuals on a genetic basis . . . protecting the confidentiality of test results will not shield all such subjects from a felt sense of stigmatization nor from personal anxieties stemming from their own misinterpretation of their carrier status. Extreme caution should therefore be exercised before steps that lend themselves to stigmatization are taken . . .⁶⁷

The cautionary theme is carried several steps further in a recent paper by Breyer and Zeckhauser.⁶⁸ They argue not only that there should be no federal control of genetic programs, but that such involvement might force issues and decisions to the surface that are better left submerged. For instance, popular belief holds that it is the physician's role to preserve life, while at the same time, as individuals, we are vaguely aware that in given situations a doctor may allow a newborn child to die, e.g., a "monster infant." While most doctors probably would not engage in questionable practices, and those few who do are undoubtedly under great stress, the authors ask whether it would be wise to force a legislature to set rules and regulations for such situations. In the words of those authors, "Can we not in some individual cases permit ethical decisions to kill, although we would forbid them were they to become elevated into the general consciousness through formulation of a legal principle?"⁶⁹

In the absence of any simple answer to this and other disturbing questions, Breyer and Zeckhauser counsel for caution on the part of the federal government, advice which seems appropriate under the current circumstances.

At this time, the outline of genetic engineering problems can be seen only dimly, if at all. Proposals to institute formal regulatory procedures in this area, for example to license or forbid varieties of genetic research, must be viewed with suspicion. On the other hand, it would surely seem appropriate for the federal government to stimulate increased study of, discussion of, and

⁶⁶ Ibid., p. 1130.

⁶⁷ Ibid., p. 1132.

⁶⁸ Stephen Breyer and Richard Zeckhauser, "The Regulation of Genetic Engineering," Paper presented to the American Academy for the Advancement of Science session on Genetics, Man, and Society, December 1972.

⁶⁹ Ibid., p. 8.

concern about, the problems of social and genetic engineering. But this would seem to be the present limit of prudent . . . government control.⁷⁰

Abortion and Other Practices

Abortion is a difficult topic related to genetic counseling. Were a genetic screening, counseling, and diagnosis service to exist, abortion would be an obvious option following true positive identifications through amniocentesis or *in utero* assessment techniques yet to be developed and perfected.

With respect to rubella detection, one preventive technique reported by Ruben as being practiced in Scandinavia is that

the expectant mother has a blood titre drawn at the beginning of her pregnancy and again at the end of the third month of the pregnancy. If the rubella titre has become elevated during that time, she is advised of the possibility that she may have had a sub-clinical infection of rubella. A decision can be made at that time as to whether or not the pregnancy should be continued.⁷¹

While recent court decisions have helped clarify abortion as a medical practice, the case is far from closed. In an assessment of the practice made in 1969, Beck and her associates stressed many important research issues, several of which had clear policy implications.⁷² The discussion and the research issues appear to have continuing validity.

Prevention of handicapping via sterilization as a family planning practice is, if anything, an even more controversial subject—a point underscored in recent revisions and clarifications of Department of Health, Education, and Welfare guidelines on the practice in federally funded programs.⁷³

⁷⁰ *Ibid.*, pp. 10-11. The general subject is as important as it is complex. Representative literature on the topic of genetic screening and counseling, and on the genetic origins of many hearing disorders, is summarized in the following: J. R. Sorenson, *Social Aspects of Applied Human Genetics*, Russell Sage Foundation, New York, 1971; E. Mendelsohn et al. (eds.), *Human Aspects of Biomedical Innovation*, Harvard University Press, Cambridge, 1971; F. C. Fraser, "Genetic Counseling and the Physician," *Canadian Medical Association Journal*, Vol. 99, 1968, pp. 927-934; WHO Expert Committee, *Genetic Counseling*, World Health Organization, Technical Report No. 416, New York, 1969; E. Beutler et al., "Hazards of Indiscriminate Screening for Sickle Cell Disease," *New England Journal of Medicine*, Vol. 285, 1971, pp. 1485-1486; C. O. Carter et al., "Genetic Clinic: A Follow-Up," *Lancet*, No. 1, 1971, pp. 281-285; B. W. Konigsmark, "Hereditary Deafness in Man," *New England Journal of Medicine*, Vol. 281, September 25, October 2, and October 9, 1969, pp. 713-720, 774-778, and 827-832; K. S. Brown, "The Genetics of Childhood Deafness," in F. McConnell and P. H. Ward (eds.), *Deafness in Childhood*, Vanderbilt University Press, Nashville, Tenn., 1967, pp. 177-202; J. H. Allen et al., "Dominantly Inherited Low-Frequency Hearing Loss," *Archives of Otolaryngology*, Vol. 8, 1968, pp. 242-250; B. Martensson, "Dominant Hereditary Nerve Deafness," *Acta Otolaryngologica*, Vol. 52, 1960, pp. 270-274; G. R. Fraser, "Profound Childhood Deafness," *Journal of Medical Genetics*, Vol. 1, 1964, pp. 118-151; C. S. Chung et al., "A Note on Deaf Mutism," *Annals of Human Genetics*, Vol. 23, 1957, pp. 357-366; W. F. Edwards, "Congenital Middle-Ear Deafness with Anomalies of the Face," *Journal of Laryngology*, Vol. 78, 1964, pp. 152-170; and P. J. Waardenburg, "A New Syndrome Combining Developmental Anomalies of the Eyelids, Eyebrows and Nose Root with Pigmentary Defects of the Iris and Head Hair and with Congenital Deafness," *American Journal of Human Genetics*, Vol. 3, 1951, pp. 195-253.

⁷¹ Robert J. Ruben, "Prevention of Deafness," in Doin Hicks (ed.), *Medical Aspects of Deafness*, Council of Organizations Serving the Deaf, National Forum Number IV, Atlantic City, N.J., March 3-5, 1971, pp. 35-45, at p. 35.

⁷² Mildred B. Beck et al., "Abortion: A National Public and Mental Health Problem—Past, Present, and Proposed Research," *American Journal of Public Health*, Vol. 59, December 1969, pp. 2131-2143. One-half of the article is devoted to a recitation of research questions. The plea for research is repeated in somewhat different form in S. H. Newman, M. B. Beck, and S. Lewit, "Abortion, Obtained and Denied: Research Approaches," *Studies in Family Planning*, Vol. 53, May 1970, pp. 1-8.

⁷³ "Doctors Scored on Sterilization," *New York Times*, October 31, 1973.

Recent sensational revelations to the effect that pediatricians in charge of an infant intensive care unit at the Yale-New Haven Hospital had given some 43 seriously deformed and impaired infants the "right to die," deserve mention as perhaps a logical-moral limit in preventive strategies. The magnificent life-saving technologies that have greatly improved medicine in the last decade or so have brought with them moral and ethical questions that demand full and humane inquiry. Should a severely impaired infant be allowed to die?⁷⁴ Bound up in this chilling question are other imponderable issues: What constitutes "severely impaired"—that is, whose definition is to prevail? Will improved technology force this definition to change over the years to the point where a relatively "minor" impairment by 1974 standards, such as a hearing or vision defect, becomes a "severe impairment" by the standards of a few decades hence? Who decides if and when the child should be allowed to die? How is one able to certify that the infant's "right to die" has been guaranteed, in the argot of the current euphemism?

It is not at all clear how these issues will be resolved, or even if they will be resolved, but they are demanding increased humane attention. As with genetic counseling, if there is to be a governmental role at all outside the courts, prudence seems to dictate that it be confined to research—not allowed to intervene in control or operations.

⁷⁴ The disclosure has attracted widespread public attention. See, for example, "43 Deformed Infants Given 'Right to Die,'" *Los Angeles Times*, October 27, 1973.

Chapter 7

SENSORY AIDS AND OTHER EQUIPMENT

INTRODUCTION

This chapter discusses various types of sensory aids and related equipment currently in use, such as corrective lenses and other optical vision enhancement devices, closed circuit television systems, talking books, large-print and braille reading material, canes, guide dogs, hearing aids, captioned films, and speech training aids.

The chapter also discusses promising devices that either are not yet fully developed or are not yet widely used, intended to aid in reading, writing, mobility, speech training, and speech perception. They include such devices as hearing aids that not only amplify but also modify the frequencies at which aural information is presented, electrocortical prostheses, and devices for converting visual information to tactile or aural information, or for converting aural information to tactile or visual information.

This chapter also briefly describes the population needing sensory aids, presents information on the costs and the effects of current and potential aids, reviews the multitude of government programs concerned with these aids, and presents recommendations for program improvement.

We believe that nearly all hearing and vision handicapped youth need and can benefit from some type of sensory aid. A majority of them, however, do not have the aids they need. For example, the device most often used is the hearing aid, yet only about one-third to one-half of the hearing handicapped youth have hearing aids, and the use of such aids depends strongly on family income. Current annual expenditures on sensory aids for handicapped youth are impossible to determine accurately because they are generally part of a larger budget in one of the many programs concerned with such devices. We can make an estimate, however, by adding known expenditures for aids described later in this chapter and in our companion report, R-1220-HEW; doing so yields a total of at least \$40 million a year in public and private expenditures, while the correct figure is probably on the order of \$50 million. To provide aids to all youth that need them would cost at least another \$50 million annually.

Nearly all types of public agencies serving handicapped youth expend some funds on sensory aids, but no agency has major responsibility for perfecting and disseminating these aids. The federal government engages in a variety of activities connected with aids: it directly provides certain aids, it funds aids through various programs, and it stimulates sensory aid development by research in still other programs. The aids themselves, however, are usually dispensed by private dealers or organizations, and private funds are often used to purchase them.

Several problems afflict current programs concerned with sensory aids. They are numerous, fractionated, and unorganized. Too few youth needing sensory aids have them. If one believes that access to an aid should be a function of the child's need, not family income, then there are inequities in distribution. Considerable progress has been made in creating new aids, but many of these are not properly tested and guided through the many steps needed to convert a promising prototype device into a rationally designed production model. And mechanisms for assuring that produc-

tion models are widely distributed among the handicapped consumers need much improvement.

Recommendations for improving the quality, quantity, and distribution of sensory aids have been divided into two groups: those that involve the sensory aids directly, and those related to complementary services that can make a sensory aids program more effective or eliminate the need for a sensory aid altogether. Sensory aids were rated as one of the top three most important services by the families we interviewed. Hearing aids and corrective lenses were the aids most often mentioned as being valuable; however, these aids may have been singled out by the families because they are the types most likely to be needed and are also the best-known aids. (Chapter 2 discusses mechanisms and potential government roles for implementing these recommendations.)

IMPROVEMENTS IN SENSORY AID PROGRAMS

- All hearing and vision handicapped youth who can benefit from sensory aids should be assured of having them. The judicious choice of an aid can make the youth functionally less handicapped, lessen his need for other special services such as education in a special classroom, and improve the effectiveness of other services such as education and job training. Most sensory aids appear to be cost-effective and to improve the youth's quality of life significantly, especially the two types of aids most often needed: corrective lenses and hearing aids. Depending on the type of aid, the youth or his parents may also need to be trained to use and maintain the device.

- Coordinated and intensified effort is needed in support of research and development programs aimed at designing and testing new aids for the handicapped, and to convert promising prototype devices into fully human-engineered production instruments. Some of the new devices currently in the research and development stages show promise of giving the visually handicapped ready access to normal printed material, and of significantly improving their mobility; and they show promise of giving the hearing handicapped significantly improved speech perception capability.

IMPROVEMENTS IN SERVICES COMPLEMENTARY TO SENSORY AIDS

Certain services are ancillary but necessary to the effective provision of sensory aids.

- Many children may not receive needed sensory aids because their handicap is not identified. In Chapter 4 we recommended screening all children for hearing and vision impairment. An early identification program would be particularly helpful to preschool hearing handicapped youth, who should be fitted with hearing aids as early as possible so that language development is facilitated.

- The provision of a direction service, as discussed in Chapter 3, could give parents and teachers needed information on the value of various types of sensory aids available, on which aids are appropriate for the child, and on where to obtain them. This direction service would coordinate the presently fragmented delivery system.

- Since an impairment can often be stabilized, alleviated, or eliminated medically or surgically, a medical specialist should examine the child before sensory aids are dispensed.

AIDS FOR THE FUNCTIONALLY BLIND AND THE PARTIALLY SIGHTED

Among the many sensory aids and other equipment for the visually handicapped are corrective lenses, other optical and electro-optical vision enhancement devices such as binoculars and closed circuit television systems, talking books, tape recorders, large-print and braille reading material, braillewriters, canes, guide dogs and other mobility aids, and devices that convert visual information to aural or tactile information (for example, the Optacon reading device and special timepieces).

Over the years, many survey papers on sensory aids and other equipment for the functionally blind and partially sighted have been published. For example, Sloan¹ has surveyed head-worn, hand-held, and stand-mounted optical magnifiers for the partially sighted, and Nye and Bliss² have surveyed various reading, writing, and mobility aids for the functionally blind and some reading and writing aids for the partially sighted. Proceedings of several conferences on aids for the visually handicapped contain detailed descriptions of various types of aids.³ In view of the thoroughness of these and other reports, we did not generate still another detailed listing and description of such devices. Rather, we have chosen to review the various types of sensory aids and other equipment that improve or show promise of improving the educational and vocational prospects, as well as the overall quality of life, of the visually handicapped population.

Recall that this report considers a person visually handicapped if the visual acuity in his better eye with corrective lenses is no better than 20/70, or if the visual field is so restricted that he cannot maneuver safely in an unfamiliar environment without the assistance of a guide dog, cane, or sighted person. An acuity that is no better than 20/70 with correction lies in the approximate range in which a person is unable to read ordinary newsprint. Of the approximately 193,000 visually handicapped youth aged 0 to 21 in the United States, only about 7 percent have either no sight or so little sight that they must be regarded as functionally blind rather than functionally partially sighted.⁴ Further, only about 30 percent of the legally blind need to be functionally blind. By functionally blind we mean the person is: visually handicapped; unable, with or without the aid of an optical or image enhancement device, to use his eyes to read printed or handwritten material as the literate sighted do or to recognize familiar objects as the illiterate sighted do; and unable to maneuver safely in an unfamiliar environment without the assistance of a guide dog, a cane, or a sighted person. As Genensky has pointed out, the problems of the partially sighted are distinctly different from those of the functionally blind, and, further, these two subsets of the visually handicapped population, in general, need distinctly different sets of services and sensory aids.⁵ However, nearly all of the

¹ L. L. Sloan, *Recommended Aids for the Partially Sighted*, National Society for the Prevention of Blindness, Inc., 1966.

² P. W. Nye and J. C. Bliss, "Sensory Aids for the Blind: A Challenging Problem with Lessons for the Future," *Proceedings of the Institute of Electrical and Electronic Engineers*, Vol. 58, No. 12, December 1970, pp. 1878-1898.

³ See, for example, *Proceedings of the International Congress on Technology and Blindness*, Vols. I-IV, American Foundation for the Blind, New York, 1963; *Proceedings of the International Conference on Sensory Devices for the Blind*, St. Dunstan's, 191 Marylebone Road, London, 1966; *Proceedings, 1972 Carnahan Conference on Electronic Prosthetics*, Report UKY TR60-72-EE4, University of Kentucky, Lexington, Kentucky, December 1972.

⁴ J. S. Kakalik, G. D. Brewer, L. A. Dougharty, P. D. Fleischauer, and S. M. Genensky, *Services for Handicapped Youth: A Program Overview*, The Rand Corporation, R-1220-HEW, May 1973.

⁵ S. M. Genensky, *A Functional Classification System of the Visually Impaired to Replace the Legal Definition of Blindness*, The Rand Corporation, RM-6246-RC, April 1970. See also L. H. Goldish, "The

visually handicapped need some type of aid when reading and writing, and all of the functionally blind and a majority of the partially sighted need some type of mobility aid.

Corrective Lenses

The most important type of sensory aid needed by the great majority of the partially sighted is corrective lenses. We were unable to locate reliable data on how many handicapped youth possess them, but it is very clear that these lenses significantly upgrade the quality of life of the partially sighted, and should improve their ability to benefit from other services such as education. At a typical cost of perhaps \$150,⁶ with replacement every three years, starting at age 2, and using an 8 percent discount rate, we calculate that lifetime average earnings would have to be increased by at least 12 cents per hour to offset the cost. If a more expensive type of optical aid were needed, costing perhaps \$300 and lasting 10 years, then the average earnings would have to increase at least 10 cents per hour to offset costs.⁷

Reading and Writing Aids

For about 150 years, braille or other embossed writing has been used for reading and writing by some of the legally blind population. At no time, however, has a majority of that population used braille—even today the figure is perhaps less than 10 percent.⁸ This is due to many factors, including the complexity of the braille code, the relatively low reading speeds usually attained, the large and awkward size of braille volumes, the limited braille literature, and a perceived stigma associated with its use by many of the newly functionally blind. Reading speeds of up to 200 words per minute have been recorded for rapid braille readers, but the average range is 60 to 120 words per minute. However, since most legally blind people can or could visually read ordinary or enlarged printed material with the aid of appropriate optical or image enhancement devices, a primary dependence on braille is not necessary.

People who can be functionally partially sighted should *not* be summarily channeled into the use of braille. The fact that they often are is due to the crude and regrettable dichotomization of the population into the sighted and the legally blind. Some partially sighted people are channeled not only into braille for reading and writing, but into mobility training with the long cane or guide dog, and hence are conditioned to act, think, and feel as if they were functionally blind. This can put severe and unnecessary restrictions on their educational and vocational opportunities.

Among the functionally blind, there has been a tendency in recent years to use taped material to supplement and sometimes replace braille, perhaps because taping can be faster than embossing braille, and is a relatively compact way to store information. Tapes have at least one serious drawback: the problem of gaining rapid access to specific items at various locations along their length.

Severely Visually Impaired Population as a Market for Sensory Aids and Services: Part One," *The New Outlook*, June 1972, pp. 183-190.

⁶ Corrective lenses typically cost \$100 to \$200 including professional fees. Low-vision aids range in cost from a few dollars for a simple magnifier, to \$1000 to \$1300 for a CCTV system, to \$3500 for an electro-optical to tactile reading device. Special low-vision spectacles typically cost \$150 to \$500.

⁷ If a 4 percent discount rate were used, the foregoing figures would be approximately 6-1/2 and 4-1/2 cents per hour, respectively.

⁸ *Rehabilitation Engineering—A Plan for Continued Progress*, Committee on Prosthetic Research and Development, National Academy of Sciences, Washington, D.C., April 1971.

Talking books in the form of tapes or records are also used by about 18 percent of the legally blind, and about 75,000 people read large-print books.⁹

Attempts have been made to speed up the rate and ease with which printed material can be converted into braille. Nye and Bliss¹⁰ describe some of the work that has gone on to achieve these goals.

Historically, most of the research and development expenditures on devices to assist the visually handicapped have been spent on projects concerned almost exclusively with the needs of the functionally blind. A 1971 National Academy of Sciences Report¹¹ indicates that at least \$1,383,000 was spent in 1970 by the Social and Rehabilitation Service, Veterans Administration, Office of Education, and the National Eye Institute on research and development concerned with such devices. Analyses of the constituent data suggest that over 90 percent of that sum was spent on projects aimed at helping less than 8 percent of the visually handicapped population, namely, the functionally blind. Even if we exclude the partially sighted who are not legally blind, our calculations indicate that more than 90 percent of the research and development dollars went to help less than 31 percent of the legally blind (i.e., the functionally blind), and hence less than 10 percent of those dollars went to help the more than 69 percent of the legally blind who are partially sighted. The research and development projects reported included those assisting the partially sighted to read printed material with their residual vision, and assisting the functionally blind to cope with printed material using one of their nonvisual senses, to read braille, and to get around with a cane or other sensing devices. The projects also include those aimed at developing methods for preparing special material for use by the functionally blind. Medical projects aimed at treating or understanding ocular pathologies are not included—such projects do not involve the design, fabrication, testing, or evaluation of a device or process aimed at helping the visually impaired to cope with their education, vocation, or the general environment. It should also be noted that the National Academy of Sciences project compilation is said to be incomplete. Even so, it is hard to believe that the heavy bias of research and development dollars and projects toward the functionally blind is due primarily to incomplete reporting.

In the past three years, the Social and Rehabilitation Service (SRS) and the Veterans Administration have made efforts to change the balance of emphasis and funding just described. For example, the SRS lent support to the research that led to The Rand Corporation's development of closed circuit TV (CCTV) systems that help the partially sighted to use their eyes to read printed and handwritten material, to write with a pen or pencil, and to carry on other operations that require precise eye-hand coordination.¹² The key to the systems' value is that magnification can be combined with increased contrast and with contrast reversal.

Some 1500 CCTV systems have been sold to date, and over 40 per month are currently being produced. They sell for under \$1500 per unit. They are being used in schools, in libraries, on the job, and in the home. The Veterans Administration and the California Department of Vocational Rehabilitation, among others, now make CCTV systems available to partially sighted clients for use in school and on the job. Reading rates of 80 to 120 words per minute are typical, and some users

⁹ National Academy of Sciences, op. cit.

¹⁰ Op. cit.

¹¹ National Academy of Sciences, op. cit.

¹² S. M. Genensky, H. E. Petersen, H. L. Moshin, R. W. Clewett, and R. I. Yoshimura, *Advances in Closed Circuit TV Systems for the Partially Sighted*, The Rand Corporation, R-1040-HEW/RC, April 1972. Neither Rand nor any of its staff engaged in research on CCTV systems for the partially sighted have any interest in any company that manufactures, distributes, or sells such systems.

reach 200 words per minute. These are approximately the same rates as are achieved with braille, but with CCTV's *all* printed or written material can be read, not just specially prepared (braille) material, and any item that will fit under the camera can be examined visually—a slide rule, for instance.

The development of CCTV aids illustrates that human engineering of devices is very important. The most successful CCTV systems are quite simple and easy to operate, and have rational designs. Roughly speaking, a CCTV system for the partially sighted consists of a TV camera, a zoom lens, a TV monitor with some added electronics, a bright light, and a moveable platform on which the item to be viewed is placed. Merely putting such parts together is not enough to produce a good CCTV system, however, and several inadequate systems have come and gone. One must carefully choose the component parts, make design modifications in either the camera or monitor or both, and configure the instrument so that the viewer can use it with ease while seated in a natural and comfortable position.

A CCTV system has certain advantages over other reading aids for the partially sighted. For example, (1) it does not require the generation of special reading material, such as large-print books, because it can present magnified images of various sizes on its TV monitor, and (2) the images can be brighter and of higher contrast than is possible with any pure optical device. It can also present an image with the contrast reversed—for example, black type on a white background can be presented as white type on a black background; and it can view low-contrast material, such as most newspaper type, and display it as high-contrast white letters on a black background or black letters on a white background. These features, too, are beyond the capability of a purely optical aid. The result is that with the aid of contrast reversal and other image enhancement techniques, many partially sighted people are able to read print with their eyes, and write with a pen or pencil, who could not handle those tasks using other types of devices.¹³

Mehr, Frost, and Apple¹⁴ made a careful comparison of optical aids and CCTV systems with the help and cooperation of 40 partially sighted veterans. They found that these veterans' reading rates were higher and reading durations were much longer with a CCTV system than with an optical aid. The veterans were also able to write much more clearly and neatly with a CCTV system. All the subjects could do this with the help of a CCTV system, but only 63 percent of them could do it with the help of an optical aid.

Among the many devices that have been explored or developed for use by the functionally blind, one of the most promising is the Optacon, which was designed by Bliss and his colleagues at Stanford University and the Stanford Research Institute, and which is now manufactured by Telesensory Systems, Inc., of Palo Alto, California. This electro-optical to tactile reading aid permits the functionally blind to read ordinary printed material, letter by letter, by moving a probe over the material with one hand and with the other hand sensing a tactile image of each letter being viewed by the probe. The probe contains an array of sensing diodes, and the trough in which the sensing index finger is placed contains a tactile sensing element corresponding to each of these diodes. When the probe views a symbol, for example, a "B", the only tactile elements that stimulate the sensing finger are those that correspond to diodes that are viewing the printed "B". According to Telesensory Systems, Inc., 200 Optacons are currently in use, and as of December 1972, the

¹³ Genensky et al., op. cit.

¹⁴ E. B. Mehr, A. B. Frost, and L. E. Apple, "Experience with Closed Circuit Television in the Blind Rehabilitation Program of the Veterans Administration, *American Journal of Optometry and Archives of the American Academy of Optometry*, Vol. 50, No. 6, June 1973, pp. 458-469.

company estimated that new orders are coming in at the rate of about 35 per month. Optacon sells for about \$3500 per unit. Telesensory Systems advertises that people read with the device at rates as high as 80 words per minute, and one official of the Veterans Administration indicated that rates of perhaps 40 to 50 words per minute were typical in his limited experience.¹⁵

At first glance, being able to read ordinary printed material at the rate of 50 words per minute does not sound very impressive. It sounds much more so, however, when we consider that after the development of Optacon and other electro-optical to tactile or electro-optical to auditory devices, it was possible for the functionally blind person to read printed material himself rather than having a sighted person read to him. To anyone who is functionally blind (or even partially sighted), being able to read even at a very low speed means less dependence upon others and more privacy and personal satisfaction. For example, a rate of 50 words per minute allows the functionally blind to read their own mail and short magazine articles. Even so, it must be recognized that such a slow rate is not conducive to reading full-length books. Consequently, Optacon and other similar devices, as currently configured, should not be looked upon as a replacement for sighted readers or for all materials in braille or on tapes or records. They should, however, be looked upon as useful supplements to the more traditional techniques for enabling the functionally blind to read.

Mach Laboratories of Dayton, Ohio, with financial support from the Veterans Administration since at least 1957, has carried on research aimed at helping the functionally blind to read ordinary printed material. We have been told by Mach Laboratories that they now have an electro-optical to auditory reading aid for the functionally blind that they intend to offer for sale. This device, the Stereotoner, uses an electro-optical probe consisting of a vertical line of sensors that is moved across the printed line by the user. The Stereotoner transmits musical tones to the user's ears. The higher and louder sounds appear to come from the user's right, and the lower and softer sounds from his left. The high notes are induced by the tops of letters like "h", "k", and "t", and the lower notes by the bottoms of letters like "g", "p", and "q". Mach Laboratories is making 85 Stereotoners. The Veterans Administration is purchasing 50 for about \$1875 each, 15 will be turned over to the National Academy of Sciences for evaluation, and 20 are for sale to any organization or person who might want them.

Work is going on at various rates at Mach Laboratories, MIT, and Haskins Laboratories on devices that scan printed material electro-optically and produce either an audible letter-by-letter spelling of words (called spelled speech) or an actual word-by-word audible rendition.

For example, Haskins Laboratories has been experimenting with a device that scans the printed word letter by letter, determines whether it has the combination and permutation of letters in its memory unit and, if it does, produces an audible rendition of the word. If it does not, it produces an audible spelling of the word.

Mach Laboratories is working on a device called the Cognodictor, which is said to be capable of recognizing both capital and lowercase letters, but not punctuation marks, numbers, and other special symbols. It produces an audible rendition of those letters, and it has some buffering capability, which permits the spelled speech to sound less mechanical—for example, "T-H-E M-A-N I-S T-A-L-L" is rendered more like "THE MAN IS TALL." The device is said to have a 2- to 3-percent error rate; and it requires that the user keep the electro-optical probe on the line, that he adjust it for differences in letter size, and that he be able to recognize the tactile image

¹⁵ Interview with R. Bennett, Veterans Administration Hospital, Palo Alto, Calif., November 1972.

revealed to four fingertips on the hand he uses to move the probe across the printed line, when and if the Cognodictor cannot recognize a printed symbol. Mach Laboratories states that the Cognodictor, which currently is said to need modification, permits reading rates of 80 or 90 words per minute.

As Nye and Bliss¹⁶ point out, the devices under design at Haskins Laboratories and at MIT, which are meant to produce speech that is adequately recognizable and appealing to the ear, will probably be expensive and far beyond the reach of the individual functionally blind user if they ever reach the production stage. They might be purchased by large libraries and other facilities, however, that serve many functionally blind people.

A subject of recent research interest and funding by the National Institutes of Health is electrocortical visual prosthesis, the stimulation of visual sensations by means of electrodes implanted in the brain. While it is possible to create arrays of visual sensations in this way, this type of prosthesis is still at an embryonic stage and it is unlikely to be of practical use to the blind in the near future.

Mobility Aids

A 1963-1964 National Health Survey¹⁷ found that 36 percent of persons who could not read newsprint used an aid such as a cane, guide dog, or other person for mobility; and a 1971 report by the National Academy of Sciences estimated that more than 50 percent of the legally blind have canes.¹⁸ According to Nye, however, only about 15 to 20 percent of the legally blind have had cane-travel training—that is, instruction in the efficient and effective use of a cane.¹⁹ Some of the visually impaired use a cane as no more than a signal to motorists and pedestrians.

The American Foundation for the Blind lists about ten organizations that raise or train guide dogs and teach functionally blind people how to use them, but only about one percent of the legally blind do so. Many people who serve the functionally blind, and some of the blind themselves, look upon these helpful creatures with disfavor, often because they believe that dependence on a dog prevents a functionally blind person from achieving genuinely independent mobility. They feel that he has a better kinesthetic grasp of the environment while using a cane, and that it forces him to handle travel problems more realistically. They may admire and love dogs, but they nevertheless look upon them as potential obstacles to a functionally blind person's obtaining a job, and they may argue heatedly that guide dogs must be walked, fed, and otherwise cared for, and hence prolong or interfere with their masters' day.

The most acceptable mobility aid to date for the functionally blind appears to be the long cane specially designed by R. E. Hoover. This simple device permits a functionally blind person to detect obstacles on or near the ground several feet in front of him, and thus gives him time to take evasive action. It does not warn him of overhanging obstacles such as scaffolding or casement windows, however, and it can fail to warn him of depressions quickly enough and of objects that might endanger his upper body. Several techniques have been tried to reduce those dangers, but

¹⁶ Op. cit.

¹⁷ *Characteristics of Visually Impaired Persons, United States, July 1963-June 1964*, National Center for Health Statistics Report, Series 10, Number 46, HEW, Washington, D.C., August 1968.

¹⁸ Op. cit.

¹⁹ P. W. Nye (ed.), *Evaluation of Mobility Aids for the Blind*, Proceedings of a Conference, June 22-23, 1970, at Airlie House, Warrenton, Virginia, sponsored by the Subcommittee on Sensory Aids of the Committee on the Interplay of Engineering with Biology and Medicine, National Academy of Engineering, Washington, D.C.

none have yet gained wide acceptance. The most promising may be the laser cane developed by Haverford College and Bionics Instruments, Inc. It is composed of the Hoover cane and three lasers, each of which scans a region of interest to the traveler: head level, mid-section, and ground level. The laser cane also has a ranging capability that indicates to the traveler roughly how far he is from a potential hazard. All three lasers trigger a single tactile warning device that presses against one of the traveler's index fingers. Two of the lasers also give him auditory warning: the head-level laser activates circuitry that produces a high-pitched sound, and the ground-level laser generates a low-pitched sound. About 18 laser canes are now in use or on order by the Veterans Administration.

The ultrasonic spectacles developed by L. Kay also appear to be of interest in conjunction with the Hoover cane. They emit an ultrasonic signal which, when reflected back from an obstacle, produces an audible binaural signal and gives the traveler some indication of the direction of and distance to the obstacle.

A less sophisticated device that also may become a useful supplement to the Hoover cane is the Travel Pathsounder, developed by Russell and the MIT Sensory Aids Evaluation and Development Center. Worn on the chest, this device detects obstructions up to six feet in front of the traveler. When it does so it emits a ticking sound that grows more rapid as the traveler gets closer to the obstacle. When he is within 30 inches of it, the ticking sound gives way to an urgent beeping.

While most partially sighted people do not or should not need to use a cane or other guidance device, they nonetheless may need some guidance instruction. By learning to use the visual cues that remain within their capability, they can do things that the normally sighted would regard as virtually impossible at first glance.

Simple and effective techniques can often be used. For example, glare frequently prevents partially sighted people from seeing whether a traffic light is red or green straight in front of them when they want to cross a street. But oftentimes they can look off at a right angle and see when the traffic light turns yellow and red for crosswise traffic. Coupling that knowledge with the sounds and sight of traffic movement, they can deduce when they have the green light with them. A skeptic may admit this is ingenious but doubt that the partially sighted could also detect oncoming cars. The answer is that most of these people can hear vehicles coming and can see what Genensky calls "the essence" or "gestalt" of the car soon enough to take precautions. After all, a pedestrian does not need to know the make and year of an oncoming car to tell whether it is a hazard.

Genensky has also described the value of binoculars as a reading, writing, and mobility aid.²⁰ They permit many partially sighted people to do such things as read the number and route name on the front of a bus, read street signs, view traffic signals and "walk-don't walk" signs, read street numbers and names of stores, and view merchandise in a store or in its show windows.

Another electro-optical to tactile aid that may prove useful to the functionally blind for mobility and other purposes has been researched by P. Bach-y-Rita.²¹ This device, called a tactile television system, converts information gathered by a TV camera into a coarse tactile image on a person's back or stomach by means of an array of vibrating electromechanical stimulators. This allows recognition of some

²⁰ S. M. Genensky, *Binoculars: A Long-Ignored Aid for the Partially Sighted*, The Rand Corporation, R-1402-HEW, November 1973.

²¹ P. Bach-y-Rita, "A Tactile Vision Substitution System Based on Sensory Plasticity," in T. D. Sterling et al. (eds.), *Visual Prosthesis: The Interdisciplinary Dialogue*, Academic Press, New York, 1971, pp. 281-290.

objects. Starkiewicz and Kuprianowicz²² have stimulated the skin of the forehead in an attempt to achieve similar results.

AIDS FOR THE DEAF AND HARD OF HEARING

Sensory aids for the hearing handicapped include hearing aids, captioned films and TV, speech training and speech perception aids that convert aural information to visual or tactile, and devices to aid activities of daily living, such as "doorbells" that flash lights and a teletype-like device for use with a telephone.

Recall that in this report we consider persons aurally handicapped if they have frequent difficulty understanding normal speech, or worse. In terms of average decibels of hearing loss in the better ear in the 500 to 2000 Hz range, that is considered to be about 40 dB or more (ISO). A summary discussion of definitions and prevalence data is contained in our companion Rand report, R-1220-HEW. A more detailed survey-document in this field has been published by the National Institute of Neurological Diseases and Stroke;²³ it notes problems with both definitions and prevalence data, but suggests that the most widely accepted definition of a deaf person is one "in whom the sense of hearing is nonfunctional for the ordinary purposes of life." In average decibels of loss in the better ear, that level is approximately in the range from 85 to 90 dB and up. Our review of prevalence data (in R-1220-HEW) suggests that approximately 50,000 U.S. youth aged 0 to 21 years can be considered deaf, and another 440,000 youth are aurally handicapped but not deaf. One new source of prevalence data is a national speech and hearing survey of a random sample of 38,884 public school subjects in the United States, which has not yet been fully reported.²⁴ Preliminary analysis of data from that survey,²⁵ which excluded students in special schools or special classes, indicates that our estimate of 490,000 hearing handicapped youth aged 0 to 21 with loss greater than 40 dB may be a little low. Consequently, our estimates of need for sensory aids may be low.

Nearly all of the 440,000 partially hearing youth—those who are aurally handicapped but not deaf—need hearing aids.²⁶ A small fraction of the hard of hearing may not be able to benefit from hearing aids, for example, those with dysacusic disturbances primarily characterized by garbled hearing. The approximately 50,000 deaf youth have distinctly different needs for aids since their sense of hearing is essentially nonfunctional. There are two different classes of deafness: congenitally deaf youth have an impairment that occurred before language and speech were acquired; adventitiously deaf youth have a sense of hearing that became nonfunctional through illness or accident, generally after language acquisition. Speech perception aids are desirable for both types of deaf youth. Speech training aids are most desirable for the congenitally deaf, but can also be useful in helping adventitiously deaf youth to maintain a reasonably high quality of speech. However, while

²² W. Starkiewicz et al., "60-Channel Electrophthalmomy with Cd SO_x Photoresistors and Forehead Tactile Elements," in *ibid.*, pp. 295-300.

²³ *Human Communication and Its Disorders: An Overview*, NINDS Monograph No. 10, Bethesda, Md., 1969.

²⁴ F. M. Hull, et al., "The National Speech and Hearing Survey: Preliminary Results," *ASHA, A Journal of the American Speech and Hearing Association*, September 1971.

²⁵ F. M. Hull and J. A. Willeford, *National Speech and Hearing Survey Progress Report, Part II*, Colorado State University, Fort Collins, Colorado, May 9, 1972.

²⁶ H. Davis and S. R. Silverman (eds.), *Hearing and Deafness*, 3d ed., Holt, Rinehart, and Winston, New York, 1970, for example, cite a hearing level of 40 dB or worse in the better ear as the range in which a hearing aid generally is needed.

high-quality hearing aids are available, much remains to be accomplished in the development of speech training and speech perception devices.

The degree of *unaided and uncorrected* hearing loss, like the degree of unaided vision loss, is not a good measure of the degree of permanent sensorial handicap, because it does not take into account how well the hearing impaired person can *function* with an aid or after medical or surgical correction. For example, a hearing impaired person can have a very severe unaided and uncorrected hearing loss due to a malfunction or degeneration of the eardrum or one or more of the small bones in the middle ear, but surgical intervention may enable him to hear so well that he has no need for a hearing aid and has little or no difficulty with normal speech. A youth's need for a sensory aid therefore should not be established until he has received an otologic examination by a qualified physician.

Hearing Aids

A hearing aid is basically a microphone to pick up sound, an electronic device to amplify and perhaps modify the sound in other ways, and an earphone. The many models available differ from one another in various ways, such as aesthetically, in the amount of sound amplification, in the relative amplification of different frequencies of sound, and in their ways of controlling very loud sounds. Some aids modify the frequencies of sound to give the person more information in the frequency range within which he can hear best. An earmold provides a tube to convey sound from the earphone to the eardrum. Historically, hearing aids made a tremendous leap forward in utility with the advent of small transistorized versions in the early 1950s.

If the inner ear and the auditory nerve or the auditory cortex in the brain are insensitive, a hearing aid may be useless; but if the problem is a lack of conduction of sound to the inner ear, a hearing aid normally yields beneficial results. Again, an otologic examination by a qualified physician may suggest a medical or surgical method of alleviating the hearing loss, and should be conducted before a hearing aid is dispensed to a child. After a hearing aid is selected, the youth or his family need information on its use, care, and maintenance as with other types of aids, and the family may need advice on how to *motivate* the child to use the aid.

Hearing aids for young children can be a problem because the instruments need to be physically robust, it is difficult to obtain good impressions of small ears for earmolds, and rapid ear growth makes it difficult to maintain good earmold fit—but early fitting is especially important to facilitate language development.²⁷

For further summary information on hearing aids, the reader can refer to several recent publications.²⁸

In addition to personal hearing aids, group hearing aids exist. I. J. Hirsh²⁹ describes the development of group aids and how they have been used in teaching persons with very serious hearing losses. One of the most successful has been the induction loop transmitter. It consists of one or more loops of wire that encompass

²⁷ F. Kleffner, "Hearing Losses, Hearing Aids, and Children with Language Disorders," *Journal of Speech and Hearing Disorders*, May 1973.

²⁸ D. Ling, "Conventional Hearing Aids: An Overview," *The Volta Review*, September 1971; E.L.H. Corliss, *Hearing Aids*, National Bureau of Standards Monograph 117, Washington, D.C., October 1970; K. W. Berger, *The Hearing Aid: Its Operation and Development*, The National Hearing Aid Society, 24261 Grand River Avenue, Detroit, Mich., 1970; *Hearing Aid Performance Measurement Data and Hearing Aid Selection Procedures, Contract Year 1970*, Veterans Administration, Report 1B 10-124, Washington, D.C., 1970.

²⁹ "Use of Amplification in Educating Deaf Children," *American Annals of the Deaf*, Vol. 113, November 1968, pp. 1046-1055.

a classroom and are connected to one or more microphones, which are used by the teacher and the students to communicate with one another. Each student wears a special hearing aid, which is equipped with an induction coil that picks up signals from the room-encompassing loop. This arrangement permits the students to move around the room freely and still listen in to the discussion.

Frequently, persons with severe hearing impairment are able, albeit unevenly, to hear sounds at frequencies below 1000 Hz and down to about 125 Hz with their residual hearing. At least two types of experimental instruments have been developed that try to take advantage of this residual capability. One is called a low-frequency, extended-range amplification system. It delivers amplified signals down to about 80 or 100 Hz. The hope is that extending the range of a hearing aid down to those frequencies, rather than settling for the conventional cut-off at 300 to 400 Hz, may give the listener auditory clues with respect to a male voice, and thus enhance the listener's chances of understanding what that voice is saying.

Another type of instrument modifies the energy distribution of the sound across frequencies and delivers more of that energy at frequencies at which the person's hearing is best. For example, the energy in the entire range of speech-sound frequencies may be shifted into a compressed lower-frequency range, or only the higher sound frequencies may be filtered out and the information transposed and presented at lower frequencies. Erber³⁰ has reviewed a number of experiments carried out to test the value of these techniques in the communication training of the hearing handicapped. He found no conclusive evidence that either technique was or was not of significant value.

Aids to hearing by means of electrocortical aural prosthesis are roughly at the same stage of development as electrocortical visual prosthesis, namely, the feasibility study stage. Research on implants in the brain is interesting and may someday result in useful sensory aids, but is unlikely to do so in the near future.

In 1962, of the binaurally hearing impaired population in the United States who could hear and understand a few spoken words without an aid, about 29 percent of those of all ages, and 31 percent of those under age 45, used hearing aids.³¹ The usage rate among families with annual incomes over \$7000 was about twice that for families with incomes under \$2000 per year. Of persons who could not hear and understand spoken words without an aid, 43 percent of those of all ages, and 40 percent of those under age 45, used a hearing aid. The basis for selecting the aid was a doctor's or clinic's prescription in about one-third of the cases; hearing aid dealers' advice accounted for another third; and the remainder based their selections on advertising, the recommendation of a layman, or on a reason unknown to us. Of persons who had ever used an aid, 68 percent of those who cannot hear and understand spoken words without an aid, and 61 percent of those who can hear and understand a few spoken words without an aid, reported they were very satisfied or fairly satisfied with the aid. While we could locate no reliable data on the use of hearing aids by children, the relatively low usage rate for persons of all ages suggests that only a fraction of the children that could benefit from a hearing aid presently have one. That fraction is probably less than one-half and may be as low as one-third.

It is clear that by improving hearing ability, these aids can significantly improve the quality of life of these handicapped youth, and also improve their ability to benefit from education and to succeed vocationally. Hearing aids generally range in

³⁰ N. P. Erber, "Evaluation of Special Hearing Aids for Deaf Children," *Journal of Speech and Hearing Disorders*, Vol. 36, No. 4, November 1971, pp. 527-537.

³¹ *Characteristics of Persons with Impaired Hearing, U.S., July 1962-June 1963*, National Center for Health Statistics Report, Series 10, No. 35, U.S. Department of Health, Education and Welfare, Washington, D.C., April 1967.

price from approximately \$100 up to \$700, with a high-quality aid typically costing \$300 to \$350. Using a typical cost of \$350 and assuming annual operating expenses of \$60, with replacement every two years for children ages 2 to 10 and every five years thereafter, and using an 8 percent discount rate, we calculate that lifetime average earnings from ages 18 to 55 would have to be increased by at least 39 cents per hour to offset the cost. At an assumed discount rate of 4 percent, the breakeven point in earnings is 19 cents per hour.

We are obliged to rely on analyses of the "breakeven point" type since no data exist on the change in economic benefits due to use of a sensory aid. Note that for simplicity we have described the breakeven point in terms of earnings alone, but other benefits may also accrue, notably a reduction in the cost of providing various services to the handicapped person. Thus, the actual earnings increase needed to offset the cost of the aid would be, say, 19 cents less some amount to account for the decrease in cost of providing other services later in the child's life. The largest cost reduction can be in education, if the aid so improves the child's hearing that he no longer requires expensive special education services. Ling reports that "owing to the use of hearing aids, a large proportion of children who formerly received their education in special schools have been able to compete and conform with their normally hearing peers in regular classes. Many severely hearing impaired children who would formerly have been trained as deaf are now correctly treated as hard of hearing."³²

While the typical cost of \$300 to \$350 for a hearing aid seems low in view of the benefits, this is by no means a negligible sum for the poor and often may be prohibitive. Recall the strong correlation between level of income and hearing aid use.

Directions for research to further improve hearing aids are outlined in a recent National Academy of Sciences report,³³ which also makes recommendations on early screening and diagnosis, methods of stimulating language development, and the distribution of existing aids and services.

In 1968, about 400,000 hearing aids were sold in the United States. A comparison of the rate of sales per 1000 population in various areas of the world reveals that the United States and Canada have relatively high usage.

1968 Sales per 1000 Population

United States and Canada	2.05
Western Europe.....	1.06
Eastern Europe and Russia	0.40
Middle and Near East.....	0.04
Far East and Oceania	0.14
Africa.....	0.02
Latin America	0.09

SOURCE: Berger, op. cit.

A later report by O. Bentzen and J. Courtois³⁴ presented data suggesting that the number of patients with hearing aids per 100,000 inhabitants was strongly dependent on government programs, as is shown below, where we cite the two countries with highest usage rates, and the two countries with the lowest usage rates, by three categories of programs.

³² Op. cit.

³³ *Directions for Research to Improve Hearing Aids and Services for the Hearing Impaired*, Committee on Hearing, Bioacoustics and Biomechanics, Working Group 65, National Academy of Sciences—National Research Council, Washington, D.C., 1972.

³⁴ "1970 World Statistical Analysis of Hearing Aid Fittings," *National Hearing Aid Journal*, October 1971.

Country and Type of Program	Patients with Hearing Aids per 100,000 Inhabitants
Hearing aids fully paid for by the state	
Denmark	483
Sweden	363
England and Wales	250
New Zealand	182
Hearing aids partly paid for by the state	
U.S.A.	237
Norway	205
Uganda	1
Ceylon	0.6
Hearing aids fully paid for by patients	
El Salvador	170
Surinam	12
Madagascar	1
Tanzania	0.1

Speech Training and Speech Perception Aids

Several surveys of aids to help the deaf learn to speak and other aids to help them understand human speech have appeared in the recent literature.³⁵ Some of the instruments they describe convert auditory information into tactile signals, such as the Vocoder built at the Speech Transmission Laboratory in Stockholm. If speech sounds are converted to tactile stimuli, for example, the deaf person receives tactile clues to what another person is saying to supplement information obtained by lipreading, and he also receives tactile feedback to help him maintain the quality of his own speech. Other instruments convert auditory information into visual signals, such as the visible speech translator (VST) built at the Bell Telephone Laboratories, and the LUCIA, built at the Speech Transmission Laboratory. If speech sounds are converted to visible displays, for example, the deaf person can be shown and trained to know what certain sounds "look like" and hence to recognize them when spoken by another person; or the displays can show him whether his own speech "looks" as it should be understandable. These visible displays can be relatively simple, such as light bulbs that are turned on by a certain tone of sound and whose brightness depends on the volume of the sound, or they can be a relatively complex electronic device that analyzes the frequency components of the sound, displays the results as a pattern on a TV-type screen for an indefinite period of time so they can be studied, and stores the video display for future reference. Advocates of audio-to-tactile speech perception and training aids for the deaf argue that the perception of time patterns and rhythms through the skin appears to resemble that encountered in hearing. Supporters of audio-to-visual speech training aids argue that visual models of desired speech patterns can be shown to a student, the student can then practice and have the results stored, and then both the student's and the

³⁵ J. M. Pickett, "Status of Speech Analyzing Communication Aids for the Deaf," *IEEE Transactions on Audio and Electrical Acoustics*, Vol. AU-20, No. 1, March 1972, pp. 3-8; idem, "Some Applications of Speech Analysis to Communication Aids for the Deaf," *IEEE Transactions on Audio and Electrical Acoustics*, Vol. AU-17, No. 4, December 1969, pp. 283-289; H. Levitt, "Speech Processing Aids for the Deaf: An Overview," *IEEE Transactions on Audio and Electrical Acoustics*, Vol. AU-21, No. 3, June 1973; H. Levitt and P. Nye, *Sensory Training Aids for the Hearing Impaired*, Subcommittee on Sensory Aids, Committee on the Interplay of Engineering with Biology and Medicine, National Academy of Engineering, Washington, D.C., 1971.

desired patterns can be analyzed and compared in detail by teacher and student. Pickett appears to have reservations concerning the value of audio-to-tactile aids, because the skin has a limited capacity for frequency analysis compared with the ear or the eye.

H. Upton of Bell Helicopter Company has developed another auditory-to-visual aid aimed at helping a profoundly deaf or even a severely hard of hearing person to supplement information obtained about other persons' speech by lipreading and the use of a hearing aid. The aid consists of a set of tiny light bulbs mounted on eyeglass frames; different bulbs flash on and off in response to different sounds in speech.³⁶

Levitt suggests that speech perception aids are as yet only of marginal assistance, but he concludes that speech training aids have already met with a "moderate degree of success."³⁷

In sum, speech training and speech perception aids hold considerable promise, but are not yet in widespread use because they have not been fully developed and methods of using them have not been fully evaluated and disseminated.

A different class of speech perception aid includes captioned films and captioned television. The technology has been developed to provide captions for network television programs, but make the captions visible only to viewers who have specially modified TV sets.³⁸ The modification reportedly costs less than \$100.

In the previous discussion of sensory aids for the visually handicapped, we cited a National Academy of Sciences Report that estimated research and development expenditures of at least \$1,383,000, or \$1.08 per patient, for the blind and partially sighted in FY 1970. The corresponding figures for the hearing handicapped were only \$702,000, or \$0.41 per patient. In view of the state of the art of sensory aids we have described, and the sizes and needs of the two populations, it appears that more emphasis than exists presently on sensory aids for the hearing handicapped would be justified, as well as increases, in general, of expenditures for research on aids for both the hearing and the vision handicapped populations.

AIDS FOR THE DEAF-BLIND

There has been a recent growth of interest in what modern technology can do to help the deaf-blind. At the outset, technologists embarking on work in this area must be aware that only a minority of deaf-blind people have no usable residual hearing *and* no usable residual vision. Most have some residual capability with one or both senses.³⁹ We in no way wish to imply that technologists should devote their efforts exclusively to that majority; but we believe it would be mistaken zeal to stake everything on finding devices or techniques for the most severely handicapped segment of the deaf-blind population.

Many of the aids developed for persons with either impaired hearing or impaired vision are adaptable to serve many of the deaf-blind, and we need not repeat our discussion of those aids here. In addition, the visual-to-tactile and aural-to-tactile conversion devices we discussed earlier, if *developed and adapted*, could prove valuable to profoundly deaf-blind youth.

³⁶ Pickett, "Status of Speech Analyzing Communication Aids."

³⁷ Op. cit.

³⁸ R. Perkins (ed.), *Proceedings of the First National Conference on Television for the Hearing Impaired*, Southern Regional Media Center for the Deaf, University of Tennessee, Knoxville, December 1971.

³⁹ L. Guldager, "The Deaf-Blind: Their Education and Needs," *Exceptional Children*, Vol. 36, November 1969, pp. 203-206.

CURRENT SENSORY AID PROGRAMS

Nearly all types of public agencies serving handicapped youth expend some funds on sensory aids, but no agency has major responsibility for perfecting and disseminating these aids. Some school systems purchase classroom sensory aids, and sometimes even personal aids. HEW's Media Services and Captioned Films Program develops and supplies sensory aid materials. The Vocational Rehabilitation agencies purchase hearing aids, corrective lenses, and other reading, writing, and mobility aids for the visually handicapped. Under the Medicaid and the Crippled Children's Service programs, states can purchase sensory aids. Welfare funds also sometimes are used for this purpose. The Library of Congress supplies talking books and braille materials through a system of regional libraries in every state.

Our companion Rand Report R-1220-HEW describes federal programs for developing, disseminating, and purchasing sensory aids. Federal agencies involved include the Bureau of Education for the Handicapped, the Library of Congress, the Veterans Administration, the Rehabilitation Services Administration, the Assistance Payment Administration, the Medical Services Administration, the Maternal and Child Health Service, the National Institutes of Health, the American Printing House for the Blind, the National Academy of Engineering, the National Academy of Science, the National Science Foundation, and the National Bureau of Standards.

The current federal role in the provision of sensory aids is heterogeneous; in some programs the federal government provides the aids directly, in other programs it provides funds for aids that are secondary to the other primary services being funded, and research is funded in many different programs.

The current system for providing sensory aids is unorganized and fractionated, with duplication in some cases, but without any mechanism for insuring that children who need sensory aids receive them. The funding of sensory aids is partially governmental, through a multitude of programs, and partially private. The actual dispensing of the two commonest types of aids, corrective lenses and hearing aids, is typically private but with governmental regulation in many states.

For example, in 1971 about 25 states licensed and regulated hearing aid dealers,⁴⁰ and other states have passed regulatory legislation since then. Some form of minimum training for dealers is generally required for licensing, and a few states specifically prohibit selling a hearing aid to a child who has not had an examination by an otolaryngologist or a written recommendation to have such an examination. A recent project sponsored by Ralph Nader describes the present hearing aid service system in detail, strongly criticizes it, and makes several recommendations for improvement, including stronger regulation of the industry.⁴¹

The mechanisms used to provide sensory aids in some other countries are distinctly different from those in the United States. K. W. Berger⁴² has reviewed foreign mechanisms for providing hearing aids; the following are some of his findings. In Australia a scheme was introduced in 1968 whereby qualified recipients might rent an aid from the government for about \$10 a year. Belgium has a governmental program wherein the hearing impaired person gets a prescription for a hearing aid and then obtains a grant, which is renewed every five years, to purchase a hearing aid, with the amount of the grant based on the type of hearing loss. Since

⁴⁰ For a digest of those states' regulations, see "Current Information: State Licensing of Hearing Aid Dealers," *National Hearing Aid Journal*, Vol. 24, No. 9, 1971.

⁴¹ E. L. Griesel and W. L. Wilson, *Paying Through the Ear: A Report on Hearing Health Care Problems*, Public Citizens Retired Professional Action Group, Public Citizen, Inc., P.O. Box 19404, Washington, D.C., 1973.

⁴² Op. cit.

1951, Denmark has furnished free hearing aids, with free replacements every five years. All hearing aids sold under Norway's health plan must be approved by a central state testing authority, and personalized hearing aids are furnished free to children under 20 years of age and parents with children under 20. Other Norwegians needing aids are given grants toward their purchase. In Sweden, children under 16 are supplied with personalized hearing aids free of charge, while for others a grant is available every 8 years toward the purchase of a hearing aid. In Switzerland, starting in 1959, the federal health insurance program has furnished free personalized hearing aids to hearing impaired persons under 65.

Chapter 8

EDUCATION

INTRODUCTION

This chapter discusses education programs for hearing and vision handicapped youth. It briefly summarizes the population needing special education assistance; reviews federal, state, and local programs providing that assistance; examines the scanty data available on the costs, economic benefits, quality-of-life effects, and equity of service distribution in these programs; and presents recommendations for improvement.

We estimate that about 379,000 hearing handicapped and 123,000 visually handicapped youth need some special assistance in obtaining an education, ranging from the provision of sensory aids only to education in a residential institution. Basically, these are youth who cannot read normal newsprint even with corrective lenses, or who have frequent difficulty understanding normal speech. At present, only about 83,000 hearing handicapped and 28,000 vision handicapped youth are served by special education programs. The structure of the education program emphasizes service to the more severely handicapped—the totally blind and the profoundly deaf. The public schools are the primary agency for delivering service, and the education program for hearing and vision handicapped youth is directed predominantly at youth aged 5 to 17 years. Current state and local expenditures for special education are \$146 million annually for hearing handicapped and \$66 million for vision handicapped youth. The corresponding federal expenditures are \$57 million and \$20 million.

The federal government's role in the education of hearing and vision impaired children is somewhat different from its role in the overall education program for the handicapped. In the overall program, the largest percentage of federal funds is used to *stimulate* state and local effort. In the education of hearing and vision impaired youth, the role appears to be more one of *direct service* or *basic service support*. The federal schools for the deaf, and Deaf-Blind Centers, are examples of heavy federal involvement in the provision of service. The P.L. 89-313 program is an example of basic service support for state-operated or state-supported schools. This different role is relatively more expensive for the federal government; while the federal government provides only 12 percent of the funds we specifically identified for all special education, it provides some 27 percent of the identified special education funds for the hearing and vision impaired. (These percentages are for special education expenditures only. If the unknown amount of regular education expenditures going to the handicapped and the unknown amount of residential mental facility expenditures going for special education were included, the federal percentage would be lowered.)

In this chapter we also attempt to put the current programs in perspective by discussing some apparent problems in the delivery of education to handicapped children: inequitable distribution of service, insufficient resources, lack of information, and gaps in service. The three most significant gaps appear to be the lack of preschool education—especially for the hearing impaired, who need early assistance in developing language and communication skills—the lack of identification of these youth, and the inadequate provision of sensory aids.

Recommendations for improving the quality and quantity of special educational services to the aurally and visually impaired can be divided into two groups: those involving the education service directly, and those involving other complementary services that also affect the child's education. Improvement of special education is especially significant to the parents of sensorially handicapped youth we surveyed; they overwhelmingly rated education as the most important service.

SUMMARY RECOMMENDATIONS FOR IMPROVEMENT

Improving Special Educational Services

- Preschool educational programs for aurally handicapped youth should be enlarged, because early intervention can be very important to the development of those children's language and communication skills. Instruction can be given directly to the child, as well as indirectly through parents, and programs to train parents to give instruction should be encouraged.

- Education agencies should be given stronger incentives and increased capabilities to provide special educational assistance to a much larger number of hearing and vision handicapped youth. Doing so would require a greater supply of special education personnel. And to permit the delivery of appropriate services, the comprehensiveness of types of special educational assistance available in each geographic region needs to be improved. At the state level, and in regions within the state if the prevalence of handicapped youth permits, assistance should be available that is appropriate to the child's age, type of handicap, and degree of handicap.

- To enable better planning, information on special education should be improved by means of research and evaluation. Information on some of the most crucial variables that present policies are based on is either totally lacking or of very poor quality.

Improving Services Complementary to Special Education

Certain services are not strictly educational, but are very important to the successful implementation of special education programs. They include identification, sensory aids, and direction services.

- Many children may not be served because their handicaps are not identified. In Chapter 4 we recommended screening all children for hearing and vision impairment.

- Sensory aids can significantly improve the child's ability to benefit from education. In Chapter 7 we recommended that these aids be available to all handicapped youth who can benefit from them.

- A direction service can aid the education process by informing parents where they can obtain services such as health care, sensory aids, or compensatory education services. Since these services often are not provided in schools, but may be essential if the student is to obtain maximum benefit from the education system, it would be very desirable to couple the school system with the Direction Center concept discussed in Chapter 3.

NEED FOR SPECIAL EDUCATIONAL ASSISTANCE

A handicapped youth's need for and right to education is generally accepted in the United States. The U.S. Office of Education has set a goal of service to all handicapped youth by 1980; numerous states have laws specifically mandating education for all handicapped youth; the families we surveyed all cited the need for education and overwhelmingly rated education as their most important service need. The courts have been active recently in mandating that mentally retarded and other types of handicapped youth be educated, and it is possible that the court rulings will be expanded in the near future to include hearing and vision handicapped youth. While there is agreement that handicapped youth need special educational assistance, there is disagreement over what constitutes a severe enough impairment to handicap the child in obtaining an education, and what special assistance should be provided.

Need is a relative matter. For our purposes here, we have adopted the following definitions of youth who need special educational assistance distinct from that given nonhandicapped youth:

- A hearing impaired youth needs such assistance if he has frequent difficulty understanding normal speech. In terms of average decibels of uncorrected hearing-loss in the better ear, that difficulty is considered to occur when the loss is approximately 40 dB or more (ISO) in the 500 to 2000 Hz range. If the loss is correctable to the point where he has little difficulty understanding normal speech, he may need no more assistance than a hearing aid and a seat near the front of the class. But if the youth is profoundly deaf, he needs a great deal of special assistance.

- A visually impaired youth needs special assistance if he is unable to read normal newsprint. In terms of acuity with correction in the better eye, that is generally considered to occur at 20/70 or worse. As with hearing impairment, the special assistance needed clearly depends on the degree of impairment.

By these definitions, about 379,000 hearing handicapped youth aged 2 to 18, and 123,000 visually handicapped youth aged 5 to 18, needed special assistance in the United States in 1970. The age of need for special assistance in education extends to the preschool years especially for the more severely aurally handicapped, who need help in developing language and communication skills.

We stress that there is a continuum of degree of need; placing children in special classes for the handicapped or in residential schools are only two ways of helping youth. Many of these youth need special assistance, such as sensory aids, but can still be educated in regular classrooms. BEH estimates¹ of those visually impaired youth in need are significantly lower than ours primarily because BEH does not include the less severely visually impaired, who may need only sensory aids.

There are major gaps in knowledge concerning what types and amounts of special educational assistance are most appropriate to meet the needs of youth with each type and degree of hearing or vision handicap; therefore, we can hardly be definitive on the subject. Later, we recommend that a major research effort be launched to fill this serious knowledge gap, especially since parents we surveyed feel education is the handicapped child's most important need, and since more money is expended on this service than on any other.

The following is a review of current education programs for hearing and vision handicapped youth. For a more detailed description of these programs, refer to Sec.

¹ The U.S. Bureau of Education for the Handicapped estimates that children aged 0 to 19 who needed, service in FY 1969 numbered 69,800 and 400,900 for the vision and hearing handicapped, respectively.

6 of our companion report,² from which data appearing here are drawn unless otherwise indicated.

CURRENT STATE AND LOCAL EDUCATION PROGRAMS

As they do for the "normal" child, state and local governments bear the major responsibility for the education of the handicapped child. Table 8.1 presents data for their expenditures for special education, and on the number of children served. (For more detail, such as a breakdown by state, see our companion report, R-1220-HEW.)

Hearing and vision handicapped youth receive some 9 percent (\$212 million) of total state and local expenditures (\$2,364 million) on special education of the handicapped, although they constitute only 3.7 percent of those served. This disparity arises primarily because the unit costs of education programs are higher for these children than for some other handicapped children, such as the speech-impaired. However, these costs appear high partly because of the way special education expenditures are budgeted. Services rendered to handicapped children in regular schools are often not counted in special education expenditures—for example, their share of such costs as education in the classroom with normal children, libraries, maintenance, and utilities. In a residential program, however, all of these costs are counted as special education expenditures. Since the proportion of handicapped youth in residential schools is greater for hearing and vision than it is for other handicaps, there is naturally some upward bias in the relative cost of their programs. It is estimated that at least 20,000 hearing handicapped and 10,000 vision handicapped children are served in state-operated or state-supported schools, many of them residential.³ The remainder are served by local education agencies.

Table 8.1

STATE AND LOCAL EDUCATION PROGRAMS FOR HEARING
AND VISION HANDICAPPED CHILDREN:
FY 1973 ESTIMATES

Type of Handicap	Expenditures	Number Reported Served
Hard of hearing	\$ 55,000,000	55,000
Deaf	91,000,000	28,000
Visually handicapped	66,000,000	28,000
Total	\$212,000,000	111,000

CURRENT FEDERAL PROGRAMS

Federal Assistance for Education of the Handicapped consists of numerous programs under a variety of agencies. A capsule review of those that serve the hearing

² J. S. Kakalik, G. D. Brewer, L. A. Dougharty, P. D. Fleischauer, and S. M. Genensky *Services for Handicapped Youth: A Program Overview*, The Rand Corporation, R-1220-HEW, April 1973.

³ U.S. Bureau of Education for the Handicapped, *Aid to the States Information System, National Report*, September 1971, p. 9, hereafter cited as *National Report*. This is the number of children receiving aid through the P.L. 89-313 program.

and vision handicapped is given below. These programs can be put into one of three classifications, according to whether funds are used primarily for direct support of instruction, for indirect support through the production of educational resources such as teachers and audiovisual material, or for research.

Direct Support of Education

Education of the Handicapped Act (EHA), Part B. Under provisions of this Act, grants are made to the states to support education of handicapped children through initiation, expansion, or improvement of programs at the preschool, elementary school, and secondary school levels. The stated purpose is to stimulate state and local investments in special education. In 1970, an estimated 12 percent of program funds went to hearing handicapped children and 4 percent to visually handicapped children. Assuming these percentages were the same in 1972, of total expenditures of \$37.5 million, \$4.5 million went to hearing and \$1.5 million to vision handicapped children.

Elementary and Secondary Education Act (ESEA) Title I. Grants are provided to local education agencies for the education of children from low-income families. These funds are used to expand and improve educational programs for educationally deprived children. Handicapped children can also benefit from Title I, in three ways:

1. Handicapped children make up part of the educationally deprived population, and as such they can benefit from the increase in school resources along with their nonhandicapped peers.

2. Title I can be used to provide special education services to handicapped children where state law does not mandate such services. It has been estimated that \$28 million was given to local education agencies in FY 1972 under Title I for that purpose. Data are not available on the distribution of these funds among handicaps, but it probably resembles that of EHA Part B funds, which also are expended in accord with the priorities of state and local officials. If so, it is estimated that in FY 1972 \$3.4 million was directed to hearing and \$1.1 million to vision handicapped children. These and some of the later estimates in this section are based on assumptions that must be made because of the dearth of available data, a situation we recommend be rectified.

3. Under an amendment to Title I (P.L. 89-313), schools for the handicapped supported or operated directly by the state are eligible for grants. In 1970, according to the *National Report*, 18 percent of program funds under P.L. 89-313 went to hearing and 6.4 percent to vision handicapped children. Assuming these percentages were the same in 1972, \$10 million was spent on hearing and \$3.6 million on vision handicapped children.

ESEA Title III: Supplemental Education Centers and Services, Guidance, Counseling and Tests. This title is intended to help schools develop and establish exemplary elementary and secondary school educational programs to serve as models for the regular school program. States are required to spend at least 15 percent of their allotment on the handicapped. The reporting on the number and type of handicapped children served under this program is not adequate for making reliable estimates of the distribution of expenditures among handicapped groups. However, assuming that expenditures are distributed the same as EHA Part B funds, it is estimated that \$2.4 million went to hearing and \$0.8 million to vision handicapped children.

Headstart: Economic Opportunity Act. A new provision in the legislation authorizing the Headstart program requires that 10 percent of the nationwide enrollment opportunities be reserved for handicapped children. This program has not

been established long enough to indicate what types of handicapped children will be served. If we assume that these expenditures will follow the same pattern as for EHA Part B program funds, then \$4.0 million will be spent on hearing and \$1.3 million on vision handicapped youth.

Vocational Education Act of 1963, As Amended. This act provides that 10 percent of the vocational education funds allocated to each state must be spent on the handicapped. Again, the allocation of those funds among handicap groups is not known. If we again assume funds are allocated in the same manner as EHA Part B expenditures, it is estimated that of the total of \$38.4 million set aside for handicapped children under this act, \$4.6 million went to hearing and \$1.5 million to vision handicapped children in FY 1972.

Higher Education Act Amendments of 1968. This Act provides for grants to colleges and universities to help them develop programs for the disadvantaged. It has been estimated that \$0.4 million was spent on all the handicapped in FY 1972. Given the small size of this program, we have not estimated the expenditures for sensorially impaired youth, since those funds would not make a significant difference in the total amount going to hearing and vision handicapped youth.

Federally Sponsored Schools for the Deaf. The federal government sponsors several schools for the deaf: Gallaudet College; the Kendall School for deaf children; the Model Secondary School for the Deaf; and the National Technical Institute for the Deaf. The total spent on these programs in 1972 was \$14.5 million.

Special Target Groups. The federal government sponsors two relevant educational programs for special target groups. EHA Part C provides model *centers for deaf-blind children*. In 1972, \$7.5 million was spent for these centers. Although a child has to be *both* hearing and vision handicapped to be eligible for service, for our calculations we have divided the funds equally between the two categories.

The *Early Childhood Education* section of EHA supports demonstration programs in preschool education for handicapped children. Early education is especially important for the more severely aurally handicapped youth, since it is in this age period that a child learns the fundamental communication skills. Unless the auditory handicap is identified and remedial action taken, the child's development may be significantly retarded. This program had expenditures of \$7.5 million in 1972. Of the 24 projects originally funded under this program, only three were for hearing handicapped children and none were for visually handicapped children.⁴ Assuming that the composition in original projects is representative of present expenditures, \$0.9 million would be spent on hearing and nothing on vision handicapped children (but some funds probably now go to the visually handicapped).

Federal Programs for Instructional Support

The federal government also sponsors programs that produce resources for special education. Teaching personnel are developed under two programs: *EHA Part D* and the *Education Professions Development Act (P.L. 90-35)*. In the absence of data on the specialization of personnel trained under these two programs, we apportioned funds in accordance with an estimate of the number of teachers presently serving each type of handicapped child. This estimation method is subject to error when there is a change in emphasis among handicap groups. The estimated expenditures under EHA Part D were \$2.3 million for hearing and \$1.1 million for vision hand-

⁴ U.S. Bureau of Education for the Handicapped, *Handicapped Children Early Education Assistance Act (P.L. 90-538), Selected Data from Project Proposals*, September 1969.

icapped youth. Corresponding expenditures under EPDA were an estimated \$0.4 and \$0.2 million, respectively.

Regional Resource Centers are sponsored under *EHA Part C*. These centers develop curricula, train personnel, and disseminate information about effective practices in the instruction of the handicapped. In the absence of data it is assumed that the costs of this program can be allocated to each handicap in proportion to its share of EHA Part B expenditures. This means that an estimated \$0.4 million went to hearing and \$0.1 million to vision handicapped youth.

Under *EHA Part F*, captioned films are made available to the deaf, a National Center of Educational Media and Materials for the Handicapped is supported, and media related research is funded. The National Center and other depositories around the country can aid local school districts in supplementing their media inventory. While some of the activities sponsored under this section can be directly allocated to handicapped groups, most cannot. After a careful review of these activities, it appeared that of the \$10.5 million appropriation, approximately \$4.8 million was for services to hearing and \$1.3 million to vision handicapped youth.

Another media program supported by the Federal government is the *American Printing House for the Blind* (APHB) in Lexington, Kentucky. APHB provides books and other material for the visually impaired. Federal expenditures under this program were \$1.6 million in 1972.

The *Library of Congress* also sponsors a media program that provides free loan books and magazines and records for the "blind and physically handicapped." It has been estimated that a little over \$1 million was spent on visually handicapped youth.

Federal Research Programs

A significant percentage of the federal funds devoted to the handicapped could be classified as research expenditures. ESEA Title III and EHA Part B are devoted at least partially to experimentation in methods of education for the handicapped. For the purposes of this report, however, "research" is limited to that item termed research in the authorizing legislation.

EHA Part E provides for research grants and demonstration programs in the education of the handicapped. Actual expenditures for hearing and vision handicapped youth were \$1.3 and \$1.1 million, respectively, in 1971.⁵

Federal Emphasis on the Sensorially Handicapped

The distribution of funds for hearing and vision handicapped youth among the three categories, Direct Support of Education, Instructional Support, and Research, corresponds generally with that for all handicaps. Of the total for these two groups, an estimated 80 percent is spent on direct education (see Table 8.2). For all handicap groups this percentage is 77 percent.

The federal government lends relatively heavier support to the education of hearing and vision handicapped children, however, than it does to the overall education program for the handicapped. It was found that the largest percentage of funds for all types of handicapped youth combined was used to stimulate state and local effort in special education. The federal role in the education of youth with impaired hearing or vision appears to be one of more direct service and basic support, in addition to stimulation. The federally supported schools for the deaf, the Deaf-Blind

⁵ U.S. Congress, House Subcommittee of Committee on Appropriations, *Hearings, Part 2, Office of Education and Special Institutions*, 92d Cong., 2d sess., 1972, p. 433.

Table 8.2

FEDERAL EDUCATION EXPENDITURES ON HEARING
AND VISION HANDICAPPED YOUTH

(In \$ million)

Program	Type of Handicap		
	Hearing	Vision	Total
<i>Direct support of education</i>	48.1	13.6	61.7
EHA Part B	4.5	1.5	6.0
ESEA Title I			
Local education agencies	3.4	1.1	4.5
P.L.89-313	10.0	3.6	13.6
ESEA Title III	2.4	0.8	3.2
Headstart	4.0	1.3	5.3
Vocational Education Act	4.6	1.5	6.1
Federal schools for the deaf	14.5	0.0	14.5
Special target groups			
Deaf-blind centers	3.7	3.7	7.5
Early education	0.9	0.0	0.9
<i>Instructional support</i>	7.9	5.3	13.2
Teaching personnel			
EHA Part D	2.3	1.1	3.4
Education Professions Development Act	0.4	0.2	0.6
Regional resource centers (EHA Part C)	0.4	0.1	0.5
Media			
American Printing House for the Blind	0.0	1.6	1.6
Library of Congress	0.0	1.0	1.0
EHA Part F	4.8	1.3	6.1
<i>Research: EHA Part E</i>	1.3	1.1	2.4
Total	57.3	20.0	77.3

Centers, and the American Printing House for the Blind are examples of heavy federal involvement in the direct provision of service. The P.L. 89-313 program is an example of basic service support to state-operated and state-supported schools for the handicapped. This difference in role emphasis is relatively more expensive for the federal government; while it provides only 12 percent of the funds for all special education, it provides 27 percent of the estimated \$289 million expended for special education of hearing and vision handicapped youth.

Many explanations are possible for this differential federal role. First, the state-operated and supported schools receiving P.L. 89-313 funds have relatively heavy emphasis on the sensorially impaired. Second, vision and hearing impairments are the two handicaps of lowest incidence, which implies that some programs must be at the national level to achieve economies of scale. The higher education programs for the deaf, the Deaf-Blind Centers, and the educational media production programs are three examples where federal or multistate involvement could be justified to achieve such economies. Third, the relative political strength of the various handicap groups historically has shaped the present federal program. The visually handicapped, for example, are generally regarded as having strong political power through their various lobby groups.

COSTS AND EFFECTIVENESS OF THE CURRENT PROGRAMS

Lack of Information for Planning

Reliable analyses of the cost and effectiveness of special educational services require information that is not presently available. Given the high cost and importance of these services, this lack of essential planning information is critical, and we recommend a major federal effort to rectify the situation. The program is attested to by the U.S. Office of Education's own evaluation report.⁶ In that report's evaluations of all education programs serving the handicapped, all but two contained a statement like the following: "No formal evaluations have yet been conducted of this program and its effectiveness cannot be ascertained from reports now available." And the remaining two programs were "evaluated" in that report in terms of the number of teachers trained and the volume of media services offered.

In brief, no one has sufficient information to adequately evaluate the effect of any of these special education programs. At the project level, evaluation information is often required as a condition of funding, but our observations suggest that such project level evaluations are more often perfunctory than substantive.

In the absence of reliable evaluation information, we venture some order-of-magnitude estimates in the following subsections.

Program Cost

In our companion Rand report, R-1220-HEW, we estimate that the average annual special education expenditure per child served in the United States is \$879 for all handicaps combined, but ranges from \$197 for the speech impaired, to \$1247 for the hard of hearing, to \$3043 for the visually impaired, to \$4767 for the deaf. Since the speech impaired generally are served on a part-time basis by itinerant specialists, the \$197 figure is thought to be the excess cost of serving one such child above the average regular education expenditures of \$776 per child. However, since most deaf children are not educated in a classroom with "normal" children, the \$4767 figure is thought to be close to the total annual cost of educating one such child; hence we arrive at an excess cost of \$4767 minus \$776, or about \$4000 per year using current methods of education and the current average student-teacher ratio of about 6 to 1.⁷ Since the average reported annual special education expenditure per hard of hearing child served in the United States is \$1247, the corresponding excess cost for hard of hearing youth would be between approximately \$1247 (if one assumes that reported expenditures were all for youth in regular classes), and approximately \$471 (if one assumes that reported expenditures were all for special classes for the handicapped); an average excess cost of approximately \$800 is probably the correct order of magnitude.

Using the same reasoning, the average excess cost for visually handicapped youth is between \$2267 and \$3043; an estimate of approximately \$2600 is probably the correct order of magnitude. Of course, this is for current methods of educating these children, and could reasonably be as high as \$4000 for the totally blind and as low as \$800 for the partially sighted. We caution that if services were to be expanded to reach *all* aurally and visually handicapped youth, the mix of types and

⁶ U.S. Office of Education, *Annual Evaluation Report on Education Programs, FY 1972*, March 1973.

⁷ Average student-teacher ratios used here and later in this section were calculated from data in U.S. Bureau of Education for the Handicapped, *Handicapped Children in the U.S. and Special Education Personnel Required*, August 1970.

degrees of handicaps would change, and hence the overall average costs would change.

One recent study of costs⁸ indicated major variations in reported special education costs among school districts, which partially reflect differences in the special education programs offered and partially reflect variations in resource prices and accounting methods.

Economic Benefits

Data are not available on future earnings and future services required as a function of the type and amount of special education given to a child. Hence, we cannot say definitively if these expenditures are justified on an economic benefits basis. We can, however, say what these economic benefits would have to be in order to justify special education on a purely economic benefits basis. (This is a very narrow way of measuring program effect. We do not subscribe to it, and we will discuss other criteria of effect shortly.)

Let us assume that a child receives special education services at an excess cost of \$800 a year for 12 years. He then enters the labor force and works until he is 55. What increase in monthly income will equal the cost of special education if both costs and income are discounted at 8 percent? The answer is that the handicapped child must earn some \$108 a month more after receiving special education services to justify the program in these simplistic terms. It is not difficult to conceive of the 12 years of special education raising the earnings of the handicapped by this small amount—about 63 cents an hour. Thus, it appears that extra expenditures on the order of \$800 per year can be justified on purely economic benefits terms (however, data are not available to prove this conclusively.) On the other hand, the increase in earnings necessary to offset a \$4000 per year excess expenditure for special education is about \$540 a month. Expenditures of \$4000 per year for a severely handicapped child may or may not be justified on purely economic benefits terms; however, economic benefits are only one of many factors that should be considered.

Academic Achievement

Difficulties also are encountered when the effectiveness of special education programs is considered from the viewpoint of academic achievement. While studies of the intelligence of hearing and vision handicapped children indicate that as a group they generally are normal, they are still handicapped in their ability to learn by their impairment in receiving or communicating information. Consequently, both students and education agencies may have to exert a great deal of extra effort if these youth are to reach normal academic achievement levels. While the data on achievement testing of these youth are incomplete and not representative of all sensorially handicapped students, they suggest that there is significant room for improvement. For example, test results for 12,000 hearing impaired students in special educational programs throughout the United States indicated that they were achieving at a grade equivalent level approximately half that of normal schoolchildren.⁹

Similar types of data on visually handicapped children were not located.

⁸ R. A. Rossmiller, J. Hale, and L. Frohreich, *Educational Program for Exceptional Children: Resource Configurations and Costs*, University of Wisconsin, Madison, 1970.

⁹ *Academic Achievement Test Performance of Hearing Impaired Students: United States*, Office of Demographic Studies Report, Series D, Number 1, Gallaudet College, Washington, D.C., 1969. This is one in a series of publications that provide much useful information on current education programs for the hearing impaired.

Quality-of-Life Effects

In our companion report, we suggested several scales for measuring the effects of a program on the quality of life of handicapped youth. Since statistically reliable data are not available to use any of those scales, we are forced to rely on opinion: the parents we surveyed gave extremely high ratings to the value of special education (see Chapter 11 for details); and the consensus in the literature and among education professionals we interviewed at the federal level, and in five states, indicates that program effects outweigh costs and that all handicapped youth should receive special educational assistance.

Since special education for the most severely handicapped may not be justifiable on purely economic benefits grounds, it also must be considered on these quality-of-life, humanitarian grounds. Again, we point out that statistically reliable comprehensive evaluations of the impacts of special education programs have not yet been conducted, nor is the abundant literature on the impacts of single projects adequate to support the major program decisions that must be made.

Of course, it is possible that the educators who say more funds should be devoted to these programs are incorrect, and that the legislators who have significantly increased funds for them are incorrect, and that the parents whose children are part of these programs are mistaken in their judgment on their usefulness. But our considered judgment is that these programs yield good and effective results.

Equity of Service Distribution

One possible objective of the service system is to distribute services equitably or "fairly"—for example, to give similar treatment to every handicapped child with the same type and degree of disability. But by nearly any definition of equity that might be chosen, the distribution of special education services is grossly inequitable. In terms of the likelihood of a 5-to-17-year-old youth receiving any special educational assistance, the variation across states is extreme: from apparently serving less than 10 percent of the visually handicapped in two states to serving most of them in five other states; from apparently serving less than 10 percent of the hearing handicapped in five states to serving most of them in at least four other states. (These figures are obtained by applying national prevalence data to the individual states.) Using BEH estimates of the prevalence of youth aged 5 to 17 needing special educational assistance, we estimate that 21 percent of the hard of hearing, 72 percent of the deaf, and 55 percent of the visually impaired youth were served in the United States in 1972-73.

In terms of the amount of assistance received per child in a special education program, as measured by average reported special education expenditures, the variation across states is extreme: from less than \$500 for each hearing or vision handicapped student served, in several states, to more than \$3000 in several other states.

Intrastate variations in service levels are probably as large as, if not larger than interstate ones. Given the large variation in expenditures among school districts for regular education programs, it can only be expected that these same variations hold with respect to special education. Nonetheless, a child's receipt of special educational assistance, and the amount he receives, are unmistakably and strongly dependent on where his parents live. This means that many handicapped children will either be denied educational service because of where they live, or they will be forced to move to districts where such services are available (1 in every 10 of the families we surveyed *had* moved to obtain special education for their children). Such a system is undesirable from several standpoints. First, it creates disincentives for local dis-

tricts to sponsor outstanding special education programs. If they do, they are likely to attract handicapped children from outside the district and necessarily raise the budget of the school or divert resources from the regular education program. Secondly, it requires that families having handicapped children bear the burden of moving costs, possible loss of jobs, etc., to obtain adequate public service. Thirdly, it means that the children of some who cannot or will not move will receive inadequate special education services. The analysis in our companion report, R-1220-HEW, suggests that handicapped youth receive more assistance (as measured by expenditures per child served) in higher-income states. Some of these differences in expenditures are due to price differences between states. The differences are so large, however, that most of them must be attributed to differences in service levels.

Preschool-age youth and the less severely impaired also are less likely to receive special educational assistance.

NEEDED IMPROVEMENTS IN SPECIAL EDUCATION PROGRAMS

Crucial improvements needed in the delivery of special educational assistance to hearing and vision handicapped youth are discussed here; our recommendations appear in italics.

Increase the fraction of school-age hearing and vision handicapped youth receiving special educational assistance, and concomitantly increase personnel and the comprehensiveness of special educational assistance available in each geographic area.

Principal arguments in favor of these increases are: Parents overwhelmingly point to special education as their child's most important need; these increases would reduce the inequity of present service delivery; the courts are moving in the direction of mandating such service as a "right"; such assistance appears to be cost-beneficial in an economic sense, as well as humanitarian, for the less severely handicapped; and such assistance appears to be justifiable on humanitarian grounds for the more severely handicapped.

The principal argument against this increase is the cost. If service were expanded to all youth in need aged 5 to 17 at the same excess expenditure rate prevailing for those currently served, and if we used BEH estimates of the prevalence of those youth needing service,¹⁰ then an estimated total budget increase of approximately \$269 million a year would be required (\$209 million for the aurally handicapped, \$60 million for the visually handicapped¹¹). In themselves, these are not prohibitively high expenditures. The problem of cost is primarily due to the likelihood that a school district which began serving all sensorially handicapped youth would forthwith come under extreme pressure to serve all other handicapped youth—and that would require adding about \$2.5 billion a year to special education budgets in the United States.

One might start by serving all of the blind and the deaf, since their handicaps are two of the severest and they comprise a small enough population so that certain aspects of expanding service to the total population in need could be tested at relatively low cost.

As the number of youth served grew, there would be an opportunity to expand

¹⁰ See R-1220-HEW, Sec. 6.

¹¹ These differ from the estimates in R-1220-HEW, which are not adjusted to represent expenditures in excess of those for regular educational programs.

programs in ways that would reduce the current inequity of geographic distribution. At a minimum, each state could provide a full range of types of special educational assistance appropriate to the different ages and types and degrees of handicaps. That is not done currently. If the prevalence of the types of handicapped youth permits, then services appropriate to that type of child should be available in appropriately sized intrastate regions. As an example of inappropriate service, a 1969 survey of educational programs for hearing impaired youth found that "Almost one-third of the children in the schools for the deaf are reported to be educationally hard of hearing [but the schools] are generally unable to provide the necessary special services for hard of hearing children, and instead, place the children in classes with deaf children."¹² Further, the schools for the deaf reportedly are forced to take these hard of hearing children because they are the only facilities available in the area that provide special help for the aurally handicapped.

Of course, an increase in the number of children served would require a concomitant increase in special education personnel and facilities. Using BEH estimates of the desirable ratio between students and special education teachers for the currently unserved population aged 5 to 17,¹³ we calculate that approximately 11,500 new specialists in education of the sensorially impaired are required: 9900 for the aurally handicapped and 1600 for the visually handicapped.

The question of sufficiency of resources depends on the objectives set in special education. That is, unless one knows what has to be achieved, it is impossible to calculate the resources necessary to achieve it. Objectives can be framed by answering two questions: How many children should be served? What level and type of service should be offered? It is easy to say that every child should be served, and served so generously that he reaches his maximum potential. But with the limited amount of funds available both for current programs and for incremental changes, it is necessary to make hard choices between the number of children served and the quality of service.

The current trend is to extend the program to more children rather than to increase the quality of existing programs. The implicit reasoning behind these priorities appears to be that existing programs are typically subject to minimum standards of quality (e.g., student-teacher ratios) to prevent their becoming ineffectual because of low budgets; and in many situations there are decreasing returns from investment. That is, an additional dollar spent on a child already in a program will not buy as much in effectiveness as it would buy if spent on a child who has been receiving no service. The trend to expand services to more children is logical if one considers the parents' comments to us: they were generally satisfied with the quality of special education received, but reported difficulties in getting into the programs (see Chapter 11 for details).

Potential federal activities in supporting the expansion of special education services to hearing and vision handicapped youth include: direct provision of services, financial aid to state and local governments, regulations associated with financial aid, court rulings, investment in service manpower and facilities, and stimula-

¹² F. McConnell et al., *A Study of Current Practices in Education for Hard of Hearing Children*, American Speech and Hearing Association, Washington, D.C., October 1969.

¹³ U.S. Bureau of Education for the Handicapped, *Handicapped Children in the U.S. and Special Educational Personnel Required*, Washington, D.C., August 1970. Student-teacher ratios were calculated from that document by dividing teachers (teachers needed) by the number of served (unserved) youth. The ratios for served and unserved youth are different because the population served is more severely impaired and needs more intensive service. For unserved youth the ratios of special education personnel, exclusive of regular teachers serving some of these youth, are: hard of hearing, 23 to 1; deaf, 9 to 1; visually impaired, 14 to 1. Actual ratios for currently served youth: hard of hearing, 11 to 1; deaf 6 to 1; and visually impaired, 6 to 1.

tion of service provision through research, demonstration, and information dissemination. In most other program areas the federal government uses a mixture of these activities, and in special education *all* of them exist to a limited extent. The best choice of federal role in special education will probably continue to include a hybrid mixture of these activities.

While it may be feasible for the federal government to provide all special education to handicapped youth directly, it would clearly be inefficient to bypass state and local governments, which already possess the administrative machinery and resources for regular education services. Direct federal provision of services may be justified, however, for very limited types of special educational services or for very-low-incidence population groups: in both cases, the population served is so small that it is uneconomical for a single state to mount a high-quality program on its own. For example, deaf-blind youth and profoundly deaf youth needing higher education are two very-low-incidence population groups currently served on an interstate basis. Even in these situations, however, the federal government might choose to fund a service center through a single state, with regulations for admission of youth from other states, rather than directly operate a service center without state involvement.

Federal financial aid to state and local government earmarked for special education is clearly a major feasible option. Education historically has not been an area of heavy federal involvement relative to total education expenditures from all sources. Not until the passage of the Elementary and Secondary Education Act of 1965 was the federal government a major significant supporter of local education. A basic reason for this inactivity was the view that education is state and local responsibility. Why, then, might the federal government consider becoming heavily involved in the support of special education? Let us review some of the major arguments.

An equity argument in support of federal financial aid is that poor states do not have the resources for an adequate special education program, and the federal government, while giving aid to all states, might favor poorer states and in effect transfer funds from wealthy to poor states to enhance equal special educational opportunity. Of course, every state *does have* sufficient resources to support an adequate special education program, but it must choose to do so. For example, only about 1 out of 10 school-age youth are handicapped; if state officials wanted to spend twice as much per handicapped child as per nonhandicapped child, and they increased the fraction of handicapped youth served by special education from 50 percent to 100 percent, the total education budget would need to increase by only about 5 to 7 percent, depending on one's assumptions about the percentage presently excluded from school altogether. Since primary and secondary education accounts for only about 32 percent of state and local expenditures,¹⁴ only about a 2 percent increase in total state and local expenditures would be needed to finance the needed expansion in special education services in this example. It is not fair, however, to view special education needs in isolation from the other pressing problems faced by states and localities. Poorer states are at a disadvantage in providing many social services. To provide a uniformly high standard of service could mean high state and local tax rates, which, in the long run, might not be in the best interests of the poor states or the nation as a whole. Therefore, the equity argument provides some support for allowing the federal government to help special education financially,

¹⁴ Education accounted for 40.5 percent of state and local general expenditures in 1969 (*1971 Statistical Abstract*, p. 404). Higher education accounted for 20 percent of all educational expenditures (*ibid.*, p. 403). Therefore only about 32 percent of all funds went for primary and secondary education.

thereby allowing all states, rich and poor, to provide an equivalent level of service for equal tax effort.

An externality of benefits argument in support of federal financial aid for special education is that its benefits are bestowed upon the nation as a whole, in the form of an informed and well-trained citizenry, and that federal welfare and other service costs for handicapped persons are reduced when special education is provided. According to this argument, without federal support the handicapped person, and state and local authorities, might underinvest in special education to the detriment of society, because some benefits of special education do not accrue to the single individual, state, or locality. A highly mobile populace and federal funding of other noneducation services are two causes of benefits accruing beyond state boundaries. To have a nationally optimum level of investment in special education, then, the tenor of this argument is that federal supplement is required to equate total marginal social benefits with total marginal social costs.¹⁵ Nevertheless, it is difficult to construct a case where the external (interstate) effects of special education are large in relation to the intrastate effects. The most serious deprivations inflicted by small investment in special education will be borne by the handicapped and their families, not by other citizens.

Another argument for federal financial aid for special education is that there is a large unmet service need; some level of government should meet the need; state and local governments are not meeting the need; therefore the federal government should. A counterargument is that regulation without financial aid might be sufficient, a contingency discussed later in this section. In considering this argument for financial aid, it is important to try to understand why state and local levels of government are not meeting the need. Possible explanations are that the problem is not as large as it appears; that many state and local decisionmakers do not view special education as a high-priority program; or that these unserved children would be served if they were identified. As indicated in Chapter 6 of our companion report, R-1220-HEW, the extent of unmet need is extremely large, but less than popular estimates would suggest. Moreover, it appears that state and local governments may be mobilizing greater resources for their special education programs. In 1968-69, it was reported that state and local governments spent \$1.3 billion dollars.¹⁶ Our estimate for 1972-73 of \$2.4 billion is not directly comparable, but it is clear that state and local efforts in this area are increasing. And, clearly, if the states wished to serve more handicapped youth, they could implement identification programs to find those youth. Another possible explanation for insufficiency of funds in special education rests on the institutional structure of resource allocation: who makes decisions, and the incentives facing the decisionmaker. A simplistic model of this decisionmaking process includes the public, the school board, and the superintendent. In preparing the budget, the superintendent faces pressure from both the parents and the employees of the district. Confronted by increasing costs of providing regular education, the superintendent may perhaps feel compelled to maintain support of the majority of both groups, to the disadvantage of handicapped children and their parents, a small minority by comparison.

The school board is responsive mainly to voters. Assuming that a board member wants to be reelected, coalition-building among the majority of parents and nonparents who live and vote in the school district naturally follows. Parents are primarily

¹⁵ See Samuel B. Chase, Jr., (ed.), *Problems in Public Expenditure Analysis*, The Brookings Institution, Washington, D.C., 1968, pp. 44-45, for a discussion of the analysis of external effects for public expenditure decisionmaking.

¹⁶ "Summary Statistics: Expenditures" (mimeograph). Council for Exceptional Children, Arlington, Virginia, n.d.

concerned with *regular* education, and nonparents are often resistant to increases in the tax rate; together, these two groups are a force against increasing school expenditures. Parents without handicapped children are generally concerned with visible signs of progress in their child's education, along with other indicators of the overall quality of the school. Appealing to these interests, a school board may emphasize programs that boost student achievement scores on statewide tests, intermural athletics, or drug prevention programs. Again, as with any minority group, it is hard for the handicapped to exert a heavy influence on the board's decisions.

The model presented above is overdrawn for the purpose of emphasis. Decision-making at the local school district level is not as simple as the model suggests. Our model, however, is not in basic disagreement with the findings of more careful examinations of the school budgeting process.¹⁷

While much the same arguments can be made for state-level decisionmaking, the federal government, for a variety of complex reasons, has lately been in the forefront in protecting the rights of minorities. Should federal dollars be spent in support of the handicapped minority to protect its rights? The answer is not clear, but as with other minorities, the federal government appears to be the most likely, if not the only, candidate to redress grievances. If the federal government were to undertake a large financial role in special education, the best mechanism for doing so is also unclear. Earmarking funds for special education would probably be required, presuming that general education revenue-sharing would not alter the local and state decisionmaking incentive structures that have in the past helped create a large fraction of unserved handicapped youth. *Any* noncategorical revenue-sharing aid would have this same effect. Despite a recent trend in federal funding away from categorical aid, such a shift is likely to hurt the interests of the handicapped if our model of decisionmaking has validity. Long-term, federal financial support may not be necessary to achieve desired special education objectives, nor for that matter would it even be healthy. Major impediments to increasing special education expenditures include at least the following concerns: current program inertia, large initial costs, an insufficient number of identified handicapped youth, and a lack of organized clientele demanding special education services. Each is basically a short-run phenomenon, and taken together they serve as constraints against starting programs but not against continuing them, if even at less than optimal levels. Therefore, a reasonable federal policy might be to overcome these constraints by funding start-up activities, e.g., special education teacher training, facilities construction, and identification, on a large enough scale to fill the unmet need; furthermore, the start-up problem could be lessened if the federal government were to adopt a stimulation role by funding costs of special education above the costs of regular education for perhaps five years, with a gradually decreasing federal contribution and a gradually increasing required state "match," thus allowing time for the increased state and local programs to "catch on."

If federal financial aid is given to states and localities, regulations could be implemented to earmark the funds for special education and to encourage the states to offer a comprehensive range of services to meet the needs of youth of each age, with each type and degree of handicap. Regulations governing the geographic distribution of services might also be adopted; however, such regulations are not likely to be politically feasible unless the federal government were to assume a financial role.

¹⁷ Thomas James, James A. Kelly, and Walter I. Garms, "The School Budget Process in Large Cities," in Michael W. Kirst (ed.), *The Politics of Education at the Local, State, and Federal Levels*, McCutchan Publishing Co., Berkeley, California, 1970, pp. 74-89.

Providing special educational vouchers to the handicapped population is another alternative that deserves consideration. Vouchers allow the granting agency to influence the distribution and amount of services to the handicapped, and to escape some of the institutional rigidities of the present system. As is the case with any voucher scheme, it is meant to introduce competition into the market by stimulating the supply of service and by improving the odds that matches will occur between the needs of the individual consumer and the array of services supplied.

A voucher system is no panacea, however. For one thing its potential benefits must be weighed carefully against offsetting administrative costs. For another, there may be no choice of service programs available to the parents. Also, as we have indicated, parents are usually not well-informed consumers and are rarely able to make informed decisions about the best special education program for their child. Parents may have some general familiarity with alternative curricula and teaching methods in a regular school program; but how do they evaluate specific treatments for, and the progress of, the handicapped child? Lacking performance benchmarks, they cannot do so adequately.

Currently, the federal government is heavily involved in activities intended to stimulate state and local special education efforts. However, federal resources expended in such activities are small relative to the absolute requirements implied by the Office of Education's objective to have every handicapped child receive special education by 1980. As a result, heavy reliance is placed on demonstration projects. It is commonly assumed that the influence of demonstration projects will "automatically" diffuse as word of effective practices becomes widely known, but there is little evidence to warrant this assumption.¹⁸

The courts offer another creative source for potentially powerful regulation, as evidenced in recent federal court decisions requiring state and local authorities to provide education service to certain classes of handicapped children.¹⁹ Though the courts can be and have been effective in getting some excluded children into the educational service system, this population is only a fraction of those entitled to but not receiving special education. Many handicapped children in the regular school system do not receive needed special services, or they may be ruled ineligible for service because of administrative restrictions related to age. Redressing all the inequities facing handicapped youth through court action on a case-by-case, handicap-by-handicap basis may be a feasible approach, but it is also a difficult and inefficient cure.

For court rulings to be effective, the youth must first be identified and defined according to their handicaps. But the special education needs of an impaired child are unique, and they vary markedly. It is difficult for the courts to specify exactly the quantity and quality of special education services that must be delivered, given critical individual differences in needs among the handicapped. However, courts could reaffirm the rights of equal protection of all children by requiring that special education services be given, without specifying the level of service.

Increase preschool educational opportunities for hearing handicapped youth.

The principal argument in favor of this increase is the widely accepted belief among

¹⁸ See Robert Klitgaard, *Models of Educational Innovation and Implication for Research*, The Rand Corporation, P-4977, March 1973, for a discussion of models of the bureaucracy's reaction to innovation. Rand is currently under contract with the Office of Education to see if dissemination is actually working in several of the federally sponsored education programs.

¹⁹ Alan Abeson, *A Continuing Summary of Pending and Completed Litigation Regarding the Education of Handicapped Children*, Council for Exceptional Children, Arlington, Virginia, 1972. See also Chapter 4 of this report for a more detailed discussion of court activity with respect to handicapped persons.

educators of the deaf that if a deaf child does not receive special assistance during the preschool language acquisition years, his development will be seriously and perhaps permanently inhibited. (Data are not available, however, to indicate how many youth would need less special education in later school years if they received that assistance.) For the profoundly deaf child, considerable attention is desirable; the hard of hearing child may need no more than a hearing aid so that he can develop language in the same manner as normally hearing children.

The principal arguments against this increase are cost and the lack of programs for identifying hearing-handicapped children. In Chapter 4 we recommended that a preschool-age identification program be established. As for cost, the cost of preschool-age education for the more severely hearing handicapped would not be prohibitive since we are speaking of a relatively small population. While such education might be desirable for all categories of handicapped youth, the argument for the deaf, based on the language development process as a function of age, is more compelling than any we have heard for other handicaps.

In 1970, 9959 pupils were enrolled in preschools for the deaf.²⁰ Assuming the incidence rates used throughout this study, some 62,000 children aged 3 to 5 were hard of hearing or deaf in 1970. If these figures are accurate, only 16 percent of the preschool deaf or hard of hearing children are being served—far below the corresponding school-age percentage. A recent nationwide survey²¹ indicated that, of those preschool pupils for whom a better-ear average was obtained in 1969-70, 55 percent had a hearing threshold level of 85 dB or above (ISO); and of those served whose ages at the start of education were reported, almost 40 percent began their education prior to the age of three. Thus, about half those served are those with the greatest need—the profoundly deaf—and nearly half started their preschool training at a desirable early age.

Several reasons for this shortfall in the number receiving preschool education seem evident. First, many states do not permit state-supported preschool education. Other states permit but do not mandate it. State regulation, then, offers little incentive for the local district to become involved with these handicapped children. The lack of identification of these children would of course prevent parents from seeking educational services. And even if they were identified, there are so few of these children that their parents would not constitute a very effective pressure group. Finally, no educational agency is presently responsible for service to this age group.

In reality, both hearing and vision handicapped youth could benefit from intervention in their training at an early age. The visually handicapped need training in using equipment, in mobility, and in other activities of daily living. They also need training in the use of their residual vision. The child may become dependent on others rather than develop his own capabilities. Parents, especially if they do not know what the child is capable of doing by himself, may structure his environment in such a way as to limit his opportunity for development. This blindness orientation in childhood can lead to functional blindness even if the child has some residual vision.

Federal initiative is perhaps more important for establishing preschool programs than for programs for older youth, since preschool-age groups are generally not considered a responsibility of local school districts. Children under age 5 are

²⁰ "Directory of Services for the Deaf in the United States," *American Annals of the Deaf*, Vol. 115, No. 3, 1970, p. 405.

²¹ *Characteristics of Hearing Impaired Students Under Six Years of Age, United States, 1969-1970*, Office of Demographic Studies Report, Series D, No. 7, Gallaudet College, Washington D.C., February 1972.

likely to continue to get short shrift in budget deliberations unless incentives structured by federal policy make preschool programs for hearing handicapped youth attractive.

Screen all children for hearing and vision impairment. Chapter 4 has discussed the identification of youth needing special educational assistance. It could be argued that such an identification program is not worthwhile if special education services are not locally available. Such reasoning neglects the fact that the educational environment can react differently once the handicap is identified. A teacher, for example, may be more prone to give individualized instruction if he or she knows that the child is handicapped, not lazy or inattentive. The parents could think about remedial treatment from sources other than the public school system. None of the services available from other agencies can be provided until the child is identified. Identification is important in and of itself since the problem must be recognized before it can be solved. The lack of identification may be one important reason why the education system is giving special attention to less than half the sensorially handicapped youth that need it.

Insure that sensory aids are provided to all hearing and vision handicapped youth that can benefit from them. Chapter 7 has discussed the need for and potential benefits from the provision of sensory aids. This type of equipment is especially significant to the child's education. Such aids as corrective lenses and hearing aids can often let the child stay in a regular classroom; without them, he may have to be placed in a more expensive special classroom or suffer educationally. The benefits to be gained from a sensory aid depend on a comprehensive screening program, the provision of instruction in the use, care, and value of the aid, and encouragement of the child in using it.

Increase research and evaluation to obtain better planning information. Research and evaluation can discover better ways of educating handicapped children, and document the results of existing practices. Both kinds of knowledge can be valuable to the planners of new and revised special education programs. At present, planners must proceed in the face of major information gaps. They especially need data on the size and characteristics of the served and unserved populations, and the costs, benefits, and effectiveness of various types of special educational assistance. Despite the lack of reliable information, annual special education expenditures exceed \$2.6 billion; reliable information should enable a considerably more effective allocation of these funds.

We suggest, however, that research to create better educational methods should be of a lower-order priority than the evaluation of current methods and research on how current good practices can be disseminated to all youth in need. This call for improved research and evaluation is *not* meant to imply that current special education programs are ineffective, or that the people who run them have major failings. On the contrary, these people are generally aware that information is limited about what appears to be an effective set of programs, and they are attempting to fill the gaps. We are supporting those attempts and encouraging an expanded research effort, coupled with increased efforts to disseminate and put the results of research into use.

Evaluating the effects of these programs is neither quick nor easy. They are the combined results of numerous program variables such as student ability, family characteristics, peer group characteristics, learning environment, teacher characteristics, and the like, whose relative influence is often difficult to measure.

The rationale for federal activity in research and evaluation is clear. The benefits of research and evaluation enjoyed by one state could be shared by all states.

Because of this externality of benefits, investments in research could reasonably fall below the level of what is socially optimal if such investment decisions are left to the states. And considerable duplication of effort would occur if research and evaluation were left entirely to the states.

Chapter 9

VOCATIONAL SERVICES

INTRODUCTION

This chapter discusses vocational service programs for hearing and vision handicapped youth. It briefly summarizes the need for special vocational assistance; reviews federal and state programs providing that assistance; estimates the benefits and costs of these services; and presents recommendations for improvement.

We estimate that each year approximately 33,000 hearing and vision handicapped youth enter the age range where they may need vocational services. These youth typically have the same mental and physical abilities as "normal" youth, except for their impaired hearing or vision, but their reportedly higher unemployment and underemployment rates are due to various factors, including underestimation of their abilities by potential employers. While it is true that their handicaps impede them in and may bar them from certain occupations, they can be fully productive in many others. By all rights, then, with the possible exception of the multiply handicapped, these youth should be as fully employed and earn as much as young persons who have no sensory handicaps.

The Vocational Education program described in Chapter 8 expends an estimated \$6.1 million per year for hearing and vision handicapped youth, but data are not available on program effects for these youth. Vocational or career education is not well developed even for "normal" youth, and the options available to sensorially handicapped youth through this program appear very limited.

The largest vocational service program is Vocational Rehabilitation (VR), which provided a wide variety of different services through state agencies to 6680 hearing and vision handicapped youth whose cases were closed in FY 1970. These services included diagnosis, evaluation, vocational counseling, medical and medically related restorative services, vocational training and job placement, income maintenance while participating in the program, and other services such as sensory aids, mobility training, occupational tools and equipment, and transportation. In a sense, the need for VR to provide services normally thought to be the earlier responsibility of other programs represents a shortcoming of those other programs. For example, nearly half the clients need and are provided medical or medically related services by VR.

The number of sensorially handicapped youth clients whose cases were closed in FY 1970, as a percentage of the number of such youth entering an age range where they may need VR services, was over 100 percent for deaf youth; about 10 percent for other hearing impaired youth; about 57 percent for totally blind youth; and about 21 percent for partially sighted youth. In addition, 4885 visually impaired youth who are not visually handicapped, by the definition we use in this report, had their cases closed in that year.

This program is designed to return handicapped persons to gainful employment, which may include family work, sheltered employment, or gainful homebound work, as well as competitive employment. The \$26.1 million per year expended on VR for hearing and vision handicapped youth results in an 84 percent success rate for the 52 percent of such referrals accepted, with success consisting basically of a favorable prognosis after 30 days of gainful employment. Visually impaired youth receive nearly twice the total expenditures that hearing impaired youth receive, and nearly half the expenditures for the visually impaired go for youth who either have one

good eye or some other visual impairment with acuity better than 20/70—youth who are not handicapped according to the criteria used in this report.

Across the states there is extreme variation in the number of successfully rehabilitated youth per 100,000 population aged 14 to 21. For example, the number of totally blind youth rehabilitated per 100,000 ranged from less than 0.1 to a high of 2.2. The figures for deaf youth unable to talk ranged from less than 1 to as high as 9, and for other hearing impaired youth from less than 1 to 17.

At the time of referral, only 14 percent of the rehabilitants were "gainfully employed" and over half were nonworking students; at time of closure, 86 percent were in the competitive labor market, 8 percent were homemakers, and 3 percent were employed in sheltered workshops. The average weekly earnings at closure were \$84, and about one-third earned less than \$64—the 1970 national minimum wage of \$1.60 per hour for a 40-hour workweek—despite being in the VR program for an average of 19 months from acceptance to closure, and despite basic program expenditures of \$2103 per youth rehabilitated. Expenditures per youth rehabilitated varied extremely across the states for youth with the same type and degree of handicap. They averaged, for example, \$6167 for a totally blind youth, \$2068 for a deaf youth unable to talk, and \$1678 for a youth with some other hearing impairment. Note that three times as many resources are expended per totally blind youth as are expended per deaf youth who is unable to talk.

Later in this chapter we present our benefit-cost analysis of the VR program. Our main conclusion is that the program appears to offer society a handsome return on its investment regardless of the youth's *type or degree* of hearing or vision handicap. We analyzed the sensitivity of benefits and costs to variations in the data and assumptions, and even with what we consider a demanding test using much more conservative assumptions than most previous evaluators have used, the program still appears to offer economic benefits to society and to taxpayers that exceed the costs for all eight categories of hearing and vision handicapped youth we analyzed. Add the enhanced quality of life of the youth served, and the VR program is all the more laudable.

Although the federal government provides over 80 percent of VR funds, along with program operating guidelines, states also play a major role because they operate the VR agencies and state personnel directly provide certain services such as counseling and placement (but contract with vendors for other services such as medical treatment and occupational training).

The federal government also supports State Employment Service agencies, which provided job information or placement services to about 11,000 hearing and vision handicapped youth in 1970, and expended about \$35 per client.

Other vocational programs discussed in this chapter are the Presidential, Governor's, and local Committees on Employment of the Handicapped, which primarily endeavor to educate potential employers and the public regarding the vocational abilities of the handicapped; Federal Employment of the Handicapped, a Civil Service Commission program for applicants for federal jobs; and the Randolph-Sheppard Vending Stand program, which provides visually handicapped persons with employment in governmental buildings. Exclusive of vocational education, which was discussed in Chapter 8, we estimate that all other government expenditures on vocational services for hearing and vision handicapped youth totaled \$31.6 million in FY 1972.

While the vocational service programs we investigated are of clear positive value, several problems for handicapped youth were identified. They include unemployment; little program effort to combat significant underemployment; insufficient funds to meet service needs; large inequities across states in the likelihood of being

served and in expenditures per youth served; a questionable allocation of limited available VR funds favoring visually handicapped youth over hearing handicapped youth; a similarly questionable allocation for service to relatively large numbers of youth with mild visual impairments; implicit program incentives for undesirable behavior by service personnel; insufficient service personnel with special skills in helping the hearing and vision handicapped; lack of effective coordination between various vocational service programs; inadequate outreach features in the programs; and, reportedly, low quality assistance to handicapped persons by State Employment Services in general.

Recommendations for program improvement are presented in the last section of this chapter.

NEED FOR VOCATIONAL SERVICES

The relatively higher unemployment and underemployment rates among the hearing and vision handicapped, as compared with the nonhandicapped, are thought to be due to such factors as employers' underestimation of the abilities of handicapped persons, employers' "fear of the unknown," the relatively lower educational levels of some handicapped groups, and the relatively longer on-the-job training period that may be required—but not to lower average mental ability and not to lower average physical ability (other than the ability to see or hear).¹ Although these young persons' abilities to perform in certain occupations are impaired, there is an abundance of other occupations in which they can be as productive as persons without sensory handicaps. Hence there is no physical or mental reason why they, as a group, cannot be as fully employed, as productive in the work force, and as well paid as their counterparts who have no sensory handicaps.

To set a perspective on the magnitude of this need, recall that there are about 50,000 profoundly deaf youth aged 0 to 21 in the United States, and another 440,000 hard of hearing youth who at least have frequent difficulty understanding normal speech (an average uncorrected hearing loss in the better ear in the speech frequency range of approximately 40 dB or more, ISO). There are also about 13,000 totally blind and 180,000 partially sighted youth who are unable to read normal newsprint (an acuity with correction in the better eye of approximately 20/70, or correspondingly significant restriction of visual field). More detailed definitions and prevalence data are presented in Appendix A of our companion report, R-1220-HEW. To get an order of magnitude estimate of the number of youth that would have to complete a vocational service program each year if all youth were to be served once, consider the number of hearing and vision handicapped youth that enter the potential client population each year. For example, dividing the number of youth aged 0 to 21 by 21 produces an estimate that each year about 2400 profoundly deaf, 21,000 hard of hearing, 600 totally blind, and 8600 partially sighted youth reach an age where they become part of the potential client population. That is, to keep up with the need on a continuing basis, the vocationally handicapped fraction of these approximately 33,000 hearing and vision handicapped youth must complete service each year. Of course, the distribution of ages of sensorially handicapped youth is not uniform from age 0 to 21, but in the absence of more reliable age-specific data, making that assumption allows us to make an order of magnitude approximation of the number of such youth entering the potential client population each year.

¹ See, for example, H. Davis and S. R. Silverman (eds.), *Hearing and Deafness*, 3d ed., Holt, Rinehart, & Winston, Inc., New York, 1970, Chapter 20.

In FY 1970, as detailed later in this chapter, VR case closures for deaf youth numbered 2529 (over 100 percent of the 2400 estimate just mentioned of deaf youth annually entering the client population); case closures for "other hearing impaired" youth numbered 1994 (or 9.5 percent of the 21,000 figure mentioned above); case closures for totally blind youth numbered 340 (or 57 percent of the 600 figure mentioned above); case closures for partially sighted youth, as we define them, numbered 1817 (or 21 percent of the 8600 figure mentioned above); and case closures numbered a very high 4885 for visually impaired youth who are not visually handicapped by our definitions, such as those youth with "one good eye" or "other visual impairment."²

Thus, with respect to the number in need, the VR program appears to be doing quite well in serving the most severely hearing and vision handicapped youth. It also appears to be placing relatively low emphasis on service to less severely hearing *handicapped* and to less severely visually *handicapped* youth, while placing relatively high emphasis on mildly visually *impaired* youth who are outside our definition of visually *handicapped*. Several explanations are possible for this program behavior: the mildly *visually impaired* youth may be more vocationally handicapped than the less severely *hearing handicapped* youth; the two groups may both be vocationally handicapped, but hearing handicapped youth are not as fully identified and known to the VR agency; VR counselors may be giving severely or multiply handicapped clients labels that incorrectly indicate a mild handicap, so as to lessen stigmatization; or the often-heard charge of "creaming," or accepting easy clients for service to bolster success rates, may be true for the visually impaired youth population.

The Rehabilitation Services Administration has maintained that all of these sensorially handicapped youth are vocationally handicapped and need VR services.³ If one defines need in very strict terms, such as current unemployment—ignoring potential need due to expected unemployment after school graduation and due to underemployment⁴—then some fraction of these youth would not need vocational services because they could find jobs without VR or employment service assistance. Service levels to meet the need clearly depend upon one's assumptions. At one extreme, all hearing and vision handicapped youth could be given full VR service in an attempt to prevent expected underemployment and unemployment. At the other extreme, only handicapped youth with at least, say, three months of unemployment would be given placement service, with none receiving VR services. A more moderate position would be that all profoundly deaf and totally blind youth

² While data are not available to document what constitutes "other visual impairment," our interviews with state VR personnel in California suggest that they are strabismus ("crossed eyes"), amblyopia ("lazy eye"), and relatively mild refractive errors.

³ For example, the HEW report *Hearing and Speech: Obligations Fiscal Year 1970 to Fiscal Year 1974*, the Rehabilitation Services Administration summary of programs for the deaf, the hard of hearing, and the speech impaired, indicates that "Americans who are vocationally handicapped by varying degrees and kinds of communication disorders exceed 20,000,000 in number" (p. 7), while the same report indicates that the prevalence of handicapping communicative disorders affects "over 20,000,000 Americans" (p. 2).

⁴ U.S. Department of Health, Education and Welfare, *Justification of Appropriation Estimates for Committee on Appropriations—FY 1973*, Vol. 1, p. 114, presents an estimate of youth who are "the under-employed and the unemployed (40% and 26% of handicapped school leavers, respectively)." Kenneth Trouern-Trend, *Blindness in the United States: Review of the Available Statistics with Estimates of the Prevalence of Blindness and Its Economic Impact*, The Travelers Research Center, Inc., Hartford, Connecticut, November, 1968, discusses the loss of earnings due to vision handicaps. For a discussion of the underemployment problems of deaf persons, for example, see Davis and Silverman, op. cit., and A. B. Crammatte, *Deaf Persons in Professional Employment*, Charles C. Thomas, Springfield, Illinois, 1968. J. E. Weinrich provides a summary of the literature on unemployment and earnings of deaf persons in "Direct Economic Costs of Deafness in the U.S.," *American Annals of the Deaf*, August 1972.

ed over 11,000 youth under age 22 with impaired hearing or vision. Of the youth accepted for VR services, 84 percent were successfully rehabilitated. Data on the fraction of young handicapped persons successfully placed by the Employment Service are not available. The total federal and state expenditures for VR and other employment services for sensorially impaired youth in FY 1972 were an estimated \$31,551,000 of which the federal and state shares were 83 and 17 percent, respectively. The breakdown of the expenditures by type and degree of sensorial impairment (see Table 9.1) indicates that visually impaired youth receive nearly twice the total expenditures that hearing impaired youth receive. More expenditures go for services to the less severely handicapped youth than go to the more severely handicapped, although, as we pointed out earlier, a larger fraction of the total population of more severely handicapped youth are served.

Table 9.1

SUMMARY OF EXPENDITURES FOR VOCATIONAL SERVICES
TO YOUTH, BY DISABILITY GROUP

Type and Degree of Sensorial Impairment ^a	Approximate Total State and Federal Expenditures on Handicap Group, FY 1972 ^b
Blind	\$ 2,524,000
Partially sighted, legally blind	6,626,000
Partially sighted, 20/70 up to 20/200 acuity ..	1,609,000
One good eye	5,679,000
Other visual impairment	4,259,000
Deaf, unable to talk	2,997,000
Deaf, able to talk	3,376,000
Other hearing impairment	4,480,000
 Total	 \$31,551,000

^aDefinitions of handicaps given in the U.S. Department of Health, Education and Welfare, "Statistical Reporting Procedures," *Rehabilitation Services Administration Manual*, Chapter 13, are grouped here as follows:

Blind: totally blind, no light perception (code 10).

Partially sighted--legally blind: legally but not totally blind (code 11).

Partially sighted--20/70 up to 20/200 acuity: not legally blind, but with acuity less than 20/60 with correction in the better eye, or corresponding loss of visual field (code 12).

One good eye: not legally blind, with acuity with correction in the better eye of 20/60 or better (code 13).

Other visual impairment (code 14): visual impairment not covered by codes 10 to 13, and not further defined in RSA reporting instructions to the states.

Deaf, unable to talk (code 20); deaf, able to talk (code 21), and other hearing impairments (code 22) are not further defined in the RSA reporting instructions to the states.

^bAssumes total FY 1972 expenditures are distributed across handicaps in the same proportions as were the FY 1970 basic state-federal VR program expenditures.

THE CURRENT VOCATIONAL REHABILITATION PROGRAM

The present role of the federal government is dominant. It funds 80 percent of the basic VR program; supports service to all types of physically or mentally disa-

can expect vocational difficulties and will need VR services before or just after they finish school; while less severely handicapped youth—the partially sighted and hard of hearing—would need to be screened to detect the fraction who are also significantly vocationally handicapped. That fraction would need full VR services, while the remainder would need placement assistance; and only if that placement assistance were insufficient would they receive full VR services. This latter moderate position incorporates two major concepts: there is a continuum of degree of need for vocational services, and the programs should be flexible enough to assess each youth's need and be able to respond with different levels and types of services as the youth's need changes over time.

While the number of youth needing VR service is a matter of judgment, it is apparent from our later benefit-cost analysis that this program has humanitarian and economic benefits that exceed the cost of the program for the average youth in each category of type and degree of sensory handicap. It is also apparent that benefits would increase if the program were expanded. There is little question that, at the least, placement assistance *may* be needed by each sensorially handicapped youth, since these youth all have a major handicap that limits their vocational options in ways that are not fully understood by potential employers.

The parents of the handicapped youth we surveyed⁵ rated job training and placement services as less important than education, medical care, and sensory aids, but most of them had handicapped children who were not yet of working age. Three-quarters of the youth who had worked at all had had problems, and the majority of these felt their handicap was the major reason.

OVERVIEW OF CURRENT VOCATIONAL SERVICES TO HEARING AND VISION HANDICAPPED YOUTH

This section contains an overview of current programs for the provision of vocational services to hearing and vision handicapped youth. Our companion report⁶ describes the programs in detail and presents data on services to youth with all types of physical and mental handicaps. The detailed description of vocational rehabilitation of hearing and vision handicapped youth by degree of impairment appears in this chapter; the related vocational education program was discussed in Chapter 8.

The vocational services programs are designed to help handicapped persons achieve gainful employment, which may include work in the competitive labor market, self-employment, sheltered employment, homemaking, or unpaid family work. Of the estimated total of \$202,254,000 federal and state expenditures in FY 1972 for vocational services to handicapped youth, 85 percent was for the VR program, which provides a wide variety of services (e.g., diagnosis, counseling, medical service, job training, placement, sensory aids) through state agencies. The remaining 15 percent was divided as follows: 6.0 percent for construction and improvement of facilities, 3.4 percent for training service personnel, 3.3 percent for research and development, 1.9 percent for Employment Services (primarily job information and placement), and 0.1 percent for Committees on Employment for the Handicapped (primarily endeavoring to educate potential employers and the public regarding the vocational abilities of the handicapped).

In 1970 we estimate that the VR and Employment Service programs each assist-

⁵ See Chapter 11 for details.

⁶ J. S. Kakalik, G. D. Brewer, L. A. Dougharty, P. D. Fleischauer, and S. M. Genensky, *Services for Handicapped Youth: A Program Overview*, The Rand Corporation, R-1220-HEW, May 1973.

bled persons with a substantial handicap to employment but with "high" vocational potential; allows provision of virtually any service that a client might need; supports research, the construction of physical plants, and the training of professional personnel; and gives special attention to the needs of low-incidence population groups such as the deaf-blind. Over time, federal assistance in VR has been a step-by-step progression in perceiving the unmet needs of disabled persons and providing otherwise unavailable funds to help meet those needs.

States also play a major role, however, because they operate the VR agencies, subject to federal guidelines. And state personnel directly provide certain services such as counseling and placement, and contract with public or private vendors for others such as medical services and vocational training.

The state-federal VR program objective is strictly vocational, to help physically and/or mentally handicapped persons to obtain gainful employment and lead meaningful lives. They may be provided "any goods and services necessary to render them fit to engage in a gainful occupation. . . ." The handicapped person served, however, must have a "substantial handicap to employment, which is of such a nature that vocational rehabilitation services may reasonably be expected to render him fit to engage in a gainful occupation, including a gainful occupation that is more consistent with his abilities and capabilities." That is, he must need the services and have reasonable potential to benefit from them. He may also be served to evaluate his rehabilitation potential. The term "gainful occupation" is interpreted broadly to include "employment in the competitive labor market; practice of a profession; farm or family work . . . ; sheltered employment; and home industries or other gainful homebound work."⁷

The federal role in rehabilitation is best characterized in terms of our Controllershship Model because individual states are responsible for providing rehabilitation services under federal guidelines and primarily with federal funds.

The rationales sometimes advanced for the federal rehabilitation role are the provision of otherwise unavailable resources, the needed stimulation of new devices and rehabilitation techniques, and the need for a balance-wheel redressing of fiscal inequities among the states in their ability to provide services.

In the following subsections, we are able to present detailed information on services to youth with various types and degrees of sensory handicaps because the VR program maintains a much more comprehensive management information system than do any of the other major programs we analyzed. However, the latest detailed information available for research use was from FY 1970, and the data we present on persons under age 22 were computed at The Rand Corporation from "Case Service Reports," DHEW Form RSA-300, submitted on each individual applicant at time of case closure.

Rehabilitation Act of 1973 ⁸

The Rehabilitation Act of 1973 replaces the Vocational Rehabilitation Act (29 U.S.C. 31 et seq.). The new act will revise the VR program, but will not radically change its basic aspects. The basic program will still provide grants to states, with guidelines, for provision of a wide variety of services to physically and mentally handicapped persons so that they may prepare for and engage in gainful employ-

⁷ *Federal Register*, Vol. 34, No. 200, October 1969.

⁸ P.L. 93-112, approved September 26, 1973.

ment. Emphasis is to be placed on serving first those persons with the most severe handicaps.⁹

A major provision of the proposed Rehabilitation Act of 1972,¹⁰ which would have substantially enlarged program goals by removing the restriction that the rehabilitation be strictly vocationally oriented, was not adopted. Under the Rehabilitation Act of 1973, however, a study is to be conducted to develop methods of serving persons for whom a vocational goal is not feasible.

The Act also provides for one-year advanced funding; research, including several specified projects; grants for special projects and demonstrations that hold promise of expanding or otherwise improving rehabilitation services to the handicapped, including people with spinal injuries, older blind people, the deaf, migratory agricultural workers, and seasonal farm workers. The Act also provides for a National Center for Deaf-Blind Youths and Adults; grants for construction of rehabilitation facilities; mortgage insurance for rehabilitation facilities; and funds for personnel training. The Act calls for the preparation of a long-range projection for the provision of comprehensive services to the handicapped (this provision is not limited to VR programs, and the Direction Center concept discussed in Chapter 3 may be relevant). The Office of the Secretary of HEW is given responsibility for planning, evaluation, and coordination of all programs providing services to the handicapped, and for providing a central clearinghouse for information and resource availability (in effect, the creation of a national Office for the Handicapped). The Act also establishes a federal Interagency Committee on Handicapped Employees and an Architectural and Transportation Barriers Compliance Board, and forbids discrimination against the handicapped in work done under federal grants and contracts.

Youth Caseload, FY 1970 Closures

Of the total of 22,240 hearing or vision impaired persons aged 0 to 21 who were referred to or applied for VR services with a resultant case closure in FY 1970, 11,565 (52 percent) were accepted, and of these 9704 (84 percent) were successfully rehabilitated. As shown in Table 9.2, the success rate for persons with various types and degrees of handicaps is uniformly high; none of the eight groups we analyzed had over 23 percent failures.

States have a tendency to concentrate services on the visually handicapped: 60 percent of the sensorially impaired youth served had a vision impairment, and 66 percent of the expenditures were for that group. For comparison, in the total population of U.S. youth, there are approximately equal numbers of the more severely handicapped blind and deaf youth, and the total group of hearing handicapped youth outnumbered visually handicapped youth by about 2.5 to 1.

In terms of the number of persons served, the VR program also emphasizes service to less severely handicapped youth. For example, of all the visually handicapped youth served, only 31 percent were legally blind or had acuity with correction in their better eye worse than 20/60. However, referrals with less severe impairments are more likely to be rejected than those with the more severe impairments.

For each type of sensorial handicap, Table 9.3 shows the number of successfully

⁹ As specified in the Act, the term "severe handicap" means a disability that requires multiple services over an extended period of time and results from amputation, blindness, cancer, cerebral palsy, cystic fibrosis, deafness, heart disease, hemiplegia, mental retardation, mental illness, multiple sclerosis, muscular dystrophy, neurological disorders (including stroke and epilepsy), paraplegia, quadriplegia and other spinal cord conditions, renal failure, respiratory or pulmonary dysfunction, and any other disability specified by the Secretary in regulations he shall prescribe.

¹⁰ U.S. Senate Report 92-1135.

Table 9.2
SUMMARY OF VOCATIONAL REHABILITATION OF YOUTH, BY DISABILITY GROUP^a

Type and Degree of Sensorial Impairment	Number Accepted for Service, FY 1970 Closures	Number Successfully Rehabilitated, FY 1970	Number Accepted as Percent of Number Referred, FY 1970	Number Rehabilitated as Percent of Number Accepted, FY 1970	Estimated Total State and Federal VR Expenditures on Handicap Group, FY 1972 ^b
Blind	340	263	57	77	\$ 2,000,000
Partially sighted, legally blind	1,271	994	67	78	5,500,000
Partially sighted, 20/70 up to 20/200 acuity	546	455	61	83	1,300,000
One good eye	2,511	2172	68	87	4,700,000
Other visual impairment	2,374	2030	33	86	5,600,000
Deaf, unable to talk	1,205	936	75	78	2,500,000
Deaf, able to talk	1,324	1126	66	85	2,800,000
Other hearing impairment	1,994	1728	46	87	3,700,000
Total	11,565	9704	52	84	\$26,100,000

^aData presented on persons under age 22 have been computed at The Rand Corporation from FY 1970 "Case Service Reports," DHEW form RSA-300, submitted on each individual applicant at the time of case closure.

^bAssumes total FY 1972 expenditures are distributed across handicaps in the same proportions as were the FY 1970 basic state-federal VR program expenditures.

Table 9.3

SUCCESSFULLY REHABILITATED YOUTH PER 100,000 POPULATION:
VARIOUS HANDICAP GROUPS BY STATE, FY 1970^a

U.S. Figures/ State Figures ^b	Blind	Partially Sighted-- Legally Blind	Partially Sighted-- 20/70 up to 20/200 Acuity	One Good Eye	Other Visual Impair- ment	Deaf, Unable To Talk	Deaf, Able To Talk	Other Hearing Impair- ment
Rate per 100,000 popu- lation age 14-21 in U.S.	1	3	1	7	7	3	4	5
Alabama	0.7	4	2	9	5	2	2	5
Alaska	0.0	6	2	6	10	2	8	6
Arizona ^c	0.7	2	0	0	2	3	3	1
Arkansas ^c	0.7	4	1	4	3	3	2	7
California	0.9	2	0	0	2	3	3	1
Colorado	1.1	4	1	6	6	3	5	3
Connecticut ^c	1.4	8	0	1	2	1	3	2
Delaware ^c	0.0	5	3	4	8	1	3	5
D.C.	0.9	6	0	8	30	5	5	6
Florida ^c	0.3	3	2	7	8	3	3	6
Georgia	0.8	4	2	10	9	2	3	4
Hawaii	0.9	3	2	1	3	4	2	4
Idaho ^c	0.0	2	1	10	6	4	7	12
Illinois	0.8	3	3	7	6	4	6	7
Indiana ^c	0.3	2	1	15	6	4	4	6
Iowa ^c	0.4	3	3	13	8	7	7	12
Kansas ^c	1.7	2	2	2	2	1	4	3
Kentucky	1.4	2	1	10	12	3	4	9
Louisiana ^c	0.4	5	2	24	14	1	2	17
Maine	0.0	4	1	4	5	6	4	0
Maryland	2.0	4	2	6	17	4	6	9
Massachusetts ^c	0.0	4	2	6	4	2	5	4
Michigan ^c	1.4	3	1	9	7	3	8	7
Minnesota ^c	1.0	2	1	1	1	1	2	6
Mississippi ^c	0.8	3	4	8	5	2	3	5
Missouri ^c	0.4	3	2	7	13	5	4	10
Montana ^c	0.9	2	2	19	7	2	10	11
Nebraska ^c	0.4	4	2	11	3	0	6	5
Nevada ^c	0.0	0	0	2	5	3	3	5
New Hampshire ^c	0.0	8	2	4	2	0	1	2
New Jersey	(d)	(d)	(d)	(d)	(d)	(d)	(d)	(d)
New Mexico ^c	1.2	5	1	1	2	4	6	2
New York ^c	2.2	2	1	2	2	5	4	4
North Carolina ^c	0.6	5	3	10	9	5	3	4
North Dakota	1.0	3	0	11	7	3	3	7
Ohio ^c	0.6	4	1	5	7	4	6	4
Oklahoma	0.8	3	2	18	11	3	4	9
Oregon ^c	0.6	3	1	1	2	1	2	1
Pennsylvania ^c	0.2	3	2	14	16	2	2	13
Rhode Island ^c	1.4	4	4	20	6	5	5	11
South Carolina ^c	0.0	2	1	9	9	1	5	5
South Dakota ^c	0.9	3	4	16	8	5	6	8
Tennessee ^c	0.2	5	2	8	6	4	2	7
Texas ^c	0.5	3	1	10	6	3	2	4
Utah	1.1	5	2	5	4	9	3	9
Vermont ^c	0.0	0	0	3	0	4	6	1
Virginia ^a	0.4	3	1	5	5	2	3	6
Washington ^c	0.4	2	0	2	2	3	3	4
West Virginia	1.1	6	2	14	18	7	1	14
Wisconsin	0.9	3	1	8	6	4	3	7
Wyoming	0.0	0	4	4	14	0	12	10

^aSOURCE: Rand analysis of FY 1970 "Case Service Reports."

^bState figures are rate per 100,000 population aged 14 to 21.

^cIn 1970, state had a separate VR agency for the visually handicapped, in addition to one for all other handicaps combined.

^dNot available.

rehabilitated youth per 100,000 population aged 14 to 21 in each state. The average 1970 success rates were 19 and 12 per 100,000 persons aged 14 to 21 in the United States, for vision and hearing handicapped youth, respectively, but there was extreme variation across the states. For example, the number of totally blind youth rehabilitated per 100,000 ranged from less than 0.1 to a high of 2.2 across the states; the numbers of youth with one good eye that were rehabilitated ranged from 0 to 24 per 100,000; the numbers for deaf youth unable to talk ranged from less than 1 to 9 per 100,000; and the numbers for other hearing impaired youth ranged from less than 1 to 17 per 100,000 across the states. The chances of being accepted for service also vary extremely across the states; the chances vary much more than incidence rates of the handicapping conditions can reasonably be expected to vary.

The choice of what type and severity of a person's handicap will permit acceptance into the program is up to the states within very broad federal guidelines—in some cases in a virtual absence of federal definition of what constitutes the handicap. Consequently, some states serve relatively large numbers of sensorially impaired youth, some serve very few, some emphasize service to the severely impaired, and some emphasize service to the less severely impaired while serving relatively few of the more severely impaired. The relatively high emphasis on service to the mildly visually impaired is clear.

We also addressed the question of whether a visually impaired youth is more likely to be served and rehabilitated in a state with a separate agency for VR service to the visually handicapped. Surprisingly, the average number of rehabilitations per 100,00 youth aged 14 to 21 in the state's population was higher for blind and other visually impaired youth in states *without* a special VR agency for the visually handicapped, and was approximately the same for the other three categories of visual handicap. Thus, the state VR agencies for the visually handicapped serve relatively fewer of the most mildly handicapped youth, but also serve relatively fewer of the most severely handicapped youth. So at least for youth, states with special VR agencies for the visually handicapped do not provide clearly better results in terms of the number of rehabilitations per 100,000 population. However, states with special VR agencies for the visually handicapped spend more per visually handicapped youth rehabilitated than the average of the 50 states—from a maximum of 35 percent more for totally blind youth to a minimum of 5 percent more for youth with one good eye.

Characteristics of The Recipients

Age. Nearly all young rehabilitants were over age 14. Understandably, the heaviest concentration was in the 16 to 19 age group. The totally blind are served at a slightly younger age than the other handicap groups, as shown in Table 9.4.

Education. Slightly over half the rehabilitants in each handicap group had completed high school. However, of deaf youth who were unable to talk, 42 percent were high school graduates. Approximately 20 percent of the total had completed the 9th grade or less, although (as shown in Table 9.5) that figure was 29 percent for the deaf who were unable to talk.

Secondary Sensorial Disabilities. In addition to youth primarily hearing or vision disabled, less than 1 percent of all young VR clients are reported to have secondary vision or hearing disabilities. As shown in Table 9.6, most reported secondary sensorial disabilities were the less severe types of visual or hearing impairment. Since VR personnel have no strong incentives to report secondary disabilities, they may be underreported.

Table 9.4
PERCENTAGE OF VR REHABILITANTS BY AGE GROUP,
FY 1970 CLOSURES

Type and Degree of Sensorial Handicap	Age Group				
	0-13	14-15	16-17	18-19	20-21
Blind	1.2	10.7	46.4	21.4	20.2
Partially sighted--legally blind	2.9	7.8	32.6	33.7	22.7
Partially sighted--20/70 up to 20/200 acuity	0.8	4.7	38.8	36.4	19.4
One good eye	1.4	1.7	38.0	37.9	21.1
Other visual impairment	1.7	3.1	30.5	42.1	22.6
Deaf, unable to talk	1.4	7.6	28.7	40.1	22.1
Deaf, able to talk	1.6	3.8	31.7	40.0	22.9
Other hearing impairment	2.0	3.5	34.8	38.1	21.6

SOURCE: Rand analysis of FY 1970 "Case Service Reports."

Table 9.5
PERCENTAGE OF YOUNG REHABILITANTS BY EDUCATIONAL
LEVEL, FY 1970 CLOSURES

Highest Grade Completed	Type and Degree of Sensorial Handicap							
	Blind	Partially Sighted: Legally Blind	Partially Sighted: 20/70 up to 20/200 Acuity	One Good Eye	Other Visual Impair- ment	Deaf, Unable To Talk	Deaf, Able To Talk	Other Hearing Impair- ment
0-6	5.9	5.5	2.4	1.0	2.2	10.7	5.8	3.6
7-9	16.8	18.0	11.0	9.6	14.6	18.5	14.4	12.8
10-11	25.0	25.4	27.4	26.2	27.8	29.0	27.2	28.7
12	41.6	42.7	51.6	54.4	49.5	39.1	47.6	48.7
13-20	10.8	8.5	7.5	8.8	5.9	2.7	4.9	6.3

SOURCE: Rand analysis of FY 1970 "Case Service Reports."

Table 9.6
NUMBER AND PERCENTAGE OF YOUNG VR CLIENTS WITH
SECONDARY DISABILITIES, FY 1970 CLOSURES

Type and Degree of Secondary Disability	Not Rehabilitated		Rehabilitated	
	Number ^a	Percent ^b	Number ^a	Percent ^b
Blind	0	0.0	4	0.0
Partially sighted--legally blind	0	0.0	11	0.0
Partially sighted--20/70 up to 20/200 acuity	6	0.0	16	0.0
One good eye	24	0.1	77	0.1
Other visual impairment	93	0.4	345	0.4
Total, visual impairment	123	0.5	453	0.5
Deaf, unable to talk	7	0.0	9	0.0
Deaf, able to talk	11	0.0	30	0.0
Other hearing impairment	30	0.1	134	0.2
Total, hearing impairment	48	0.2	173	0.2
Total, both impairments	171	0.7 ^c	626	0.8 ^c

^aSOURCE: Rand analysis of FY 1970 "Case Service Reports."

^bNumber as a percentage of FY 1970 closure clients with any type of primary disability.

^cColumn does not total exactly due to rounding.

Referrals

Schools are the largest single source of referrals to the VR program, sending between one-third and three-fourths of the applicants, depending on the type and degree of sensorial impairment (see Table 9.7). Medical sources are responsible for less than 15 percent of the referrals, while approximately 20 percent of the youth are self-referred or referred by a person not connected with the public or private service system for the handicapped. Problems noted are the poor coordination between VR and the schools and a deficiency in VR outreach efforts. Two prime recommendations for handicapped children by a National Citizens Advisory Committee on Vocational Rehabilitation were aimed at alleviating these problems.¹¹ Some progress in coordination has been noted in recent years, at least at the agency administration level.¹²

Only a small fraction of those not accepted for service are reported as being referred elsewhere by VR personnel (5 percent for all handicaps combined). This again stresses a need for direction, as discussed in Chapter 3.

Outcomes of Referrals to VR Agencies

Approximately half of the sensorially handicapped youth referred for VR services are not accepted; the rejection rate varies from 25 percent of deaf applicants who are unable to talk to more than 65 percent of those classified as having "other visual impairment" (see Table 9.8). Of those accepted for service, 84 percent are successfully rehabilitated; the lowest success rate reported, 73 percent, was for totally blind youth served by VR agencies that accept persons with all types of handicaps.

Despite the existence of a special VR agency for the visually handicapped in a majority of the states, only about one-quarter of the visually handicapped youth served by VR are served by VR agencies for the visually handicapped exclusively. The overall rejection and success rates for VR agencies for the visually handicapped are approximately the same as those for VR agencies serving persons with all types of handicaps; however, agencies serving only the visually handicapped tended to reject a lower percentage of the severely impaired, and a higher percentage of the mildly impaired.

The main reasons sensorially impaired youth were not accepted for VR services were: the youth refused services or failed to cooperate (35 percent of those not accepted); the youth could not be located or contacted, or had moved (12 percent); the youth was not handicapped or not vocationally handicapped (37 percent). Only 2 percent were reported as unserved because their handicap was too severe or because of an unfavorable medical prognosis. The mildly impaired were most often rejected because of the lack of a physical or vocational handicap, while the most severely impaired were most often not accepted because they were "missing persons," i.e., they reportedly could not be located or contacted, or had moved (see Table

¹¹ *Report of the National Citizens Advisory Committee on Vocational Rehabilitation*, submitted to the Secretary of Health, Education and Welfare, June 26, 1968, p. 2. Recommendations for handicapped children included "Establishment of cooperative school-rehabilitation programs in all schools, public and private, in both urban and rural locations, including a central repository of health and rehabilitation records," and "Evaluations of disabled children for rehabilitation purposes by vocational rehabilitation personnel at regular intervals . . . to help prepare the child for a meaningful adult vocational career."

¹² See, for example, M. S. Hester, Director-in-Charge, *Workshop on Evaluation and Recommendations Relating to the National Conference for Coordinating Vocational Rehabilitation and Educational Services for Deaf People*, Delgado College, New Orleans, Louisiana, February 12-13, 1971, HEW Publication No. (SRS) 72-25030.

Table 9.7
 SOURCES OF YOUTH REFERRAL TO STATE VR AGENCIES, BY HANDICAP, AND
 REFERRAL OUTCOMES, FY 1970 CLOSURES
 (In percent)

Referral Source	Blind		Partially Sighted: Legally Blind		Partially Sighted: 20/70 up to 20/200 Acuity		One Good Eye		Other Visual Impairment		Deaf, Unable to Talk		Deaf, Able to Talk		Other Hearing Impairment	
	Not Accepted	Rehabili- tated	Not Accepted	Rehabili- tated	Not Accepted	Rehabili- tated	Not Accepted	Rehabili- tated	Not Accepted	Rehabili- tated	Not Accepted	Rehabili- tated	Not Accepted	Rehabili- tated	Not Accepted	Rehabili- tated
Educational institutions	17.7	16.8	17.1	15.8	33.1	38.6	32.2	45.0	34.6	32.5	13.7	13.3	45.4	38.2	50.0	43.3
Elementary or high school	10.3	22.4	10.5	14.7	0.9	3.3	0.2	0.2	2.0	0.8	20.8	56.6	3.0	17.7	0.9	4.1
School for handicapped	4.5	2.8	4.2	5.5	3.6	5.1	3.0	4.7	2.9	6.6	2.2	2.6	2.7	4.3	2.8	3.3
Other educational institutions	3.3	2.8	1.7	1.4	0.9	2.0	0.8	1.6	1.4	2.3	1.6	1.9	1.2	1.9	1.1	1.7
Hospitals and sanatoriums	8.7	6.8	6.4	6.2	3.0	5.6	2.9	2.5	3.4	3.6	4.1	3.5	6.9	4.1	5.4	5.4
Health organizations and agencies	7.4	12.0	11.9	11.9	7.7	7.7	8.4	3.4	9.9	5.4	9.8	2.3	4.1	2.7	4.1	2.7
Welfare agencies																
Other public organizations and agencies	0.4	0.4	0.0	0.6	0.6	0.5	1.3	1.0	0.7	0.9	1.0	0.5	0.9	0.4	0.8	0.8
Correctional or court agency	2.9	1.6	1.4	1.3	8.4	5.9	9.6	6.3	10.0	10.9	6.9	2.5	4.2	3.1	5.7	4.3
Employment service	19.3	10.8	20.1	15.5	17.6	8.2	17.3	7.6	12.5	9.5	13.1	3.0	6.9	5.1	8.7	6.0
Other public organizations and agencies	0.8	2.8	0.5	1.1	1.8	0.4	1.2	0.8	1.6	1.5	2.0	1.1	2.9	2.8	3.0	5.1
Individuals																
Self-referred person	9.5	10.8	10.5	13.8	7.7	7.5	7.9	9.7	8.3	8.9	8.3	5.6	7.7	8.2	5.6	7.9
Physician	2.9	1.6	3.5	3.3	4.0	3.1	2.1	4.4	2.3	5.0	0.7	0.7	1.2	4.3	1.8	4.2
Other individual	12.3	8.4	12.1	8.7	10.2	11.5	12.7	12.7	11.2	12.2	15.4	8.6	12.9	11.2	9.9	10.9
Total	100.0	100.0	99.9	99.8	99.5	99.4	99.7	99.9	100.8	100.1	99.6	100.2	100.0	100.0	99.8	99.7

SOURCE: Rand analysis of FY 1970 "Case Service Reports."
 NOTE: Columns may not total exactly due to rounding.

Table 9.8

REFERRAL OUTCOMES BY TYPE OF VR AGENCY

Type and Degree of Sensorial Handicap	VR Agencies for the Visually Handicapped Only						VR Agencies Serving Persons with All Types of Handicaps					
	Referrals Not Served		Clients Not Rehab.		Clients Rehab.		Referrals Not Served		Clients Not Rehab.		Clients Rehab.	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Blind	140	42	38	11	157	47	115	44	39	15	106	41
Partially sighted--legally blind	403	31	214	16	694	53	231	39	63	11	300	50
Partially sighted--20/70 up to 20/200 acuity	85	36	20	8	134	56	259	40	71	11	321	49
One good eye	254	40	45	7	344	53	951	31	294	10	1828	59
Other visual impairment	1047	77	52	4	259	19	3807	65	292	5	1771	30
Deaf, unable to talk	1	100	0	0	0	0	412	25	269	17	936	58
Deaf, able to talk	2	100	0	0	0	0	684	34	198	10	1126	56
Other hearing impairment	2	100	0	0	0	0	2294	54	266	6	1728	40
All handicaps combined	1934	50	369	9	1588	41	8753	48	1492	8	8116	44

SOURCE: Rand analysis of FY 1970 "Case Service Reports."

9.9). The reasons given on the reporting forms are not nearly as informative as they might be (e.g., why did one-quarter of those not served "refuse" services?).

The prime reason for hearing and vision impaired youth not being successfully rehabilitated after they are accepted is that they "drop out," i.e., as shown in Tables 9.10 and 9.11, fully one-third either could not be located or contacted, or had moved. Another 20 percent refused service, and 12 percent "failed to cooperate." Again, these "reasons" are not very informative. The severity of the handicap was cited as the primary reason for only 6 percent of the nonrehabilitations of all sensorially impaired youth, and for less than one-fourth of those most severely impaired. Also, nearly half of those cases closed as "not rehabilitated" are closed after acceptance of the client and preparation of a plan for rehabilitation services, but before the services specified in the plan begin.

Table 9.9

REASONS YOUTH WERE NOT SERVED IN VR PROGRAM

(In percent).

Type and Degree of Sensorial Handicap	Unable to Locate or Contact, Moved	Handicap Too Severe or Unfavorable Medical Prognosis	Youth Refused Services	Death	Youth Institutionalized	Transfer to Another Agency	Failure to Cooperate	No Handicap	No Vocational Handicap	Other or Reason Not Given
Blind	21	9	15	6	2	6	7	6	3	25
Partially sighted--legally blind	22	12	17	2	1	12	8	11	3	11
Partially sighted--20/70 up to 20/200 acuity	14	1	20	1	0	8	16	13	14	14
One good eye	17	2	32	1	1	4	17	9	9	10
Other visual impairment	9	1	22	1	0	3	9	30	18	8
Deaf, unable to talk	31	3	30	0	1	2	12	2	3	17
Deaf, able to talk	15	3	22	1	0	1	16	20	13	10
Other hearing impairment	10	1	28	1	0	1	11	18	20	10
All handicaps combined	12	2	24	1	0	3	11	22	15	10

SOURCE: Rand analysis of FY 1970 "Case Service Reports."

Table 9.10

REASONS YOUTH WERE NOT REHABILITATED IN THE VR PROGRAM
(In percent)

Type and Degree of Sensorial Handicap	Unable to Locate or Contact, Moved	Handicap Too Severe or Unfavorable Medical Prognosis	Youth Refused Services	Death	Youth Institutionalized	Transfer to Another Agency	Failure to Cooperate	Other or Reason Not Given
Blind	22.0	22.1	11.7	5.2	3.9	7.8	10.4	18.2
Partially sighted--legally blind	26.6	11.9	22.3	6.5	2.8	6.6	10.2	13.3
Partially sighted--20/70 up to 20/200 acuity	31.8	6.6	16.5	5.5	0.0	14.1	8.7	16.4
One good eye	36.3	2.4	23.9	2.1	2.7	5.1	15.8	12.1
Other visual impairment	36.8	2.4	24.2	2.6	0.9	6.4	10.2	16.9
Deaf, unable to talk	35.5	8.9	13.7	2.4	1.6	2.8	10.3	24.2
Deaf, able to talk	36.7	5.0	20.2	2.0	2.0	4.5	11.1	18.6
Other hearing impairment	33.8	3.4	22.9	3.8	3.0	0.0	15.9	17.0
All handicaps combined	33.8	6.1	20.7	3.4	2.2	5.0	12.1	16.7

SOURCE: Rand analysis of FY 1970 "Case Service Reports."

Previous VR Service

About 4 percent of young hearing or vision impaired clients whose cases were closed in FY 1970 were repeat clients who had received VR services and had another case closure prior to FY 1970, and the majority of them had been successfully rehabilitated previously. Deaf youth unable to talk made up the highest fraction (7 percent) with previous case closure. (See Table 9.12).

Earnings and Sources of Support

Family and friends were the primary source of support for 81 percent of the rehabilitants at time of referral; an additional 12 percent were self-supporting from current earnings, interest, dividends, or rental income. Only 3 percent listed welfare as the primary source of support, but the comparable figure was 9 percent for the legally blind. (See Table 9.13.)

The median annual family income of rehabilitants at time of referral is approximately \$4500, i.e., half of the families have income less than that amount. Seventeen percent of the families have annual incomes under \$1800, and 21 percent receive over \$7200 per year. (See Table 9.14.)

Although only 3 percent of the young hearing or vision handicapped rehabilitants listed welfare as their primary source of support at the time of referral, 8 percent received some type of public assistance. As shown in Table 9.15, the type most frequently received in 1970 was Aid to the Blind. At the time of closure, only 3 percent received public assistance.

For successfully rehabilitated hearing and vision impaired youth in FY 1970, only 14 percent were "gainfully employed" at the time of referral, in contrast to 100 percent at time of closure. (See Table 9.16.) At time of referral, over half were nonworking students; at time of closure, 86 percent were in the competitive labor market, 8 percent were homemakers, and 3 percent were employed in sheltered workshops. The difference in work status by type and degree of handicap is most notable for the legally blind; 15 percent were in sheltered workshops at time of

Table 9.11

REASONS YOUTH WERE NOT REHABILITATED IN THE VR PROGRAM, BY TIME OF CLOSURE

(In percent)

Type and Degree of Sensorial Handicap	Unable to Locate or Contact, Moved	Handicap Too Severe or Unfavorable Medical Prognosis	Youth Refused Services	Death	Youth Institutionalized	Transfer to Another Agency	Failure to Cooperate	Other or Reason Not Given	Total
Closure from Extended Evaluation Status									
Blind	1.3	9.1	1.3	0.0	0.0	0.0	1.3	3.9	16.9
Partially sighted--legally blind	0.7	4.7	2.9	1.1	0.0	0.0	2.2	2.9	14.5
Partially sighted--20/70 up to 20/200 acuity	0.0	1.1	1.1	0.0	0.0	1.1	0.0	1.1	4.4
One good eye	0.3	0.6	0.9	0.0	0.0	0.0	0.0	0.0	1.8
Other visual impairment	0.6	0.3	1.0	0.0	0.0	0.3	0.6	1.0	3.8
Deaf, unable to talk	0.4	3.3	0.7	0.2	0.2	0.2	1.1	0.2	6.3
Deaf, able to talk	2.0	1.5	0.0	0.0	0.0	0.5	0.5	1.5	6.0
Other hearing impairment	0.0	1.1	1.1	0.0	0.0	0.0	2.3	0.8	5.3
All handicaps combined	0.6	2.1	1.1	0.2	0.1	0.2	1.0	1.1	6.2
Closure Before Rehabilitation Services Began									
Blind	3.9	3.9	6.5	1.3	2.6	1.3	0.0	2.6	22.1
Partially sighted--legally blind	8.6	2.5	11.5	1.5	0.7	1.5	3.3	4.0	33.6
Partially sighted--20/70 up to 20/200 acuity	9.8	1.1	8.8	1.1	0.0	5.4	3.3	6.6	36.1
One good eye	17.1	0.9	14.7	0.6	1.2	2.7	7.1	8.0	52.3
Other visual impairment	11.3	0.9	13.9	0.0	0.0	2.3	3.8	8.7	40.9
Deaf, unable to talk	13.7	1.9	8.5	0.7	0.7	0.4	3.0	18.4	47.3
Deaf, able to talk	11.6	0.5	11.6	0.0	1.0	1.0	6.6	10.6	43.0
Other hearing impairment	13.1	0.8	16.1	0.8	0.4	0.0	6.4	11.3	48.9
All handicaps combined	12.3	1.3	12.4	0.7	0.7	1.6	4.7	9.4	43.1
Closure After Rehabilitation Services Began									
Blind	16.8	9.1	3.9	2.6	1.3	6.5	9.1	11.7	61.0
Partially sighted--legally blind	17.3	4.7	7.9	3.9	2.1	5.1	4.7	6.4	52.1
Partially sighted--20/70 up to 20/200 acuity	22.0	4.4	6.6	4.4	0.0	7.6	5.4	8.7	59.1
One good eye	18.9	0.9	8.3	1.5	1.5	2.4	8.8	4.1	46.4
Other visual impairment	24.9	1.2	9.3	2.6	0.9	3.8	5.8	7.2	55.7
Deaf, unable to talk	21.4	3.7	4.5	1.5	0.7	2.2	6.2	5.6	45.8
Deaf, able to talk	23.1	3.0	8.6	2.0	1.0	3.0	4.0	6.5	51.2
Other hearing impairment	20.7	1.5	5.7	3.0	2.6	0.0	7.2	4.9	45.6
All handicaps combined	20.9	2.7	1.2	2.5	1.4	3.2	6.4	6.2	50.5

SOURCE: Rand analysis of FY 1970 "Case Service Reports."

Table 9.12

PERCENTAGE OF VR YOUTH CLIENTS WITH PREVIOUS CASE CLOSURES

Type and Degree of Sensory Handicap	Percent Previously "Rehabilitated"	Percent Previously "Not Rehabilitated"	Percent Not Previously Served
Blind	3.1	1.4	95.5
Partially sighted--legally blind	5.2	1.3	93.5
Partially sighted--20/70 up to 20/200 acuity	3.8	1.9	94.3
One good eye	1.8	1.4	96.8
Other visual impairment	1.9	0.8	97.3
Deaf, unable to talk	5.2	2.1	92.7
Deaf, able to talk	3.5	2.7	93.8
Other hearing impairment	3.2	1.3	95.5

SOURCE: Rand analysis of FY 1970 "Case Service Reports."

Table 9.13

YOUNG VR REHABILITANTS BY SOURCE OF SUPPORT AT TIME OF APPLICATION, FY 1970

(In percent)

Primary Source of Support	Blind	Partially Sighted: Legally Blind	Partially Sighted: 20/70 up to 20/200 Acuity	One Good Eye	Other Visual Impairment	Deaf, Unable to Talk	Deaf, Able to Talk	Other Hearing Impairment
Current earnings, interest, dividends, rent	6.5	9.1	10.6	11.3	14.6	8.1	11.6	13.4
Family and friends	75.8	77.2	83.5	83.9	74.6	84.6	83.7	81.0
Private relief agency	0.0	0.1	0.2	0.0	0.3	0.0	0.2	0.1
Public assistance, at least partly with federal funds	11.3	8.7	2.6	1.4	3.3	3.2	1.4	2.1
Public assistance, without federal funds	0.0	0.4	0.2	0.1	0.8	0.1	0.2	0.2
Public institution, tax-supported	1.7	1.6	0.4	1.1	3.3	3.0	1.2	1.5
Workmen's Compensation	0.4	0.1	0.2	0.3	0.0	0.1	0.2	0.0
Social Security Disability Insurance	2.6	1.1	0.2	0.0	0.2	0.6	0.1	0.4
Other disability, sickness, survivors, or age retirement (except private insurance); unemployment insurance benefits	1.3	1.1	1.1	1.1	0.6	0.2	0.9	0.8
Annuity and other nondisability insurance (private insurance)	0.0	0.0	0.0	0.0	0.1	0.0	0.1	0.0
Disability or sickness benefits (private insurance); savings; other sources	0.4	0.6	0.9	0.7	2.1	0.0	0.5	0.6

SOURCE: Rand analysis of FY 1970 "Case Service Reports."

Table 9.14

YOUNG VR REHABILITANTS BY MONTHLY FAMILY INCOME AT REFERRAL, FY 1970
(In percent,

Income Range (\$)	Blind		Partially Sighted: Legally Blind		Partially Sighted: 20/70 up to 20/200 Acuity		One Good Eye		Other Visual Impairment		Deaf, Unable to Talk		Deaf, Able to Talk		Other Hearing Impairment	
	Ref	Clos	Ref	Clos	Ref	Clos	Ref	Clos	Ref	Clos	Ref	Clos	Ref	Clos	Ref	Clos
0-149	26.5		21.0		17.0		14.5		19.7		17.0		11.5		13.4	
150-199	6.5		7.2		7.5		6.5		9.0		4.2		3.9		4.9	
200-249	7.1		7.5		7.5		7.6		11.1		8.7		7.3		8.0	
250-299	5.3		7.6		9.8		7.6		7.9		5.7		8.1		6.3	
300-349	8.8		9.2		9.8		11.0		9.0		9.9		6.7		8.2	
350-399	7.1		7.4		3.6		5.4		7.7		5.2		6.4		7.0	
400-449	7.1		7.0		10.6		9.8		7.1		10.6		11.8		11.3	
450-499	4.1		5.5		5.6		5.3		5.4		5.4		6.3		6.9	
500-599	7.6		8.0		10.9		11.6		20.0		10.3		11.4		11.5	
600 and over	20.0		19.5		17.6		20.6		14.0		23.0		26.6		22.5	
Total	100.0		100.0		100.0		100.0		100.0		100.0		100.0		100.0	

SOURCE: Rand analysis of FY 1970 "Case Service Reports."

Table 9.15

PERCENTAGES OF REHABILITATED YOUTH IN PUBLIC ASSISTANCE CATEGORIES, FY 1970 CLOSURES

Assistance Category	Blind		Partially Sighted: Legally Blind		Partially Sighted: 20/70 up to 20/200 Acuity		One Good Eye		Other Visual Impairment		Deaf, Unable to Talk		Deaf, Able to Talk		Other Hearing Impairment	
	Ref	Clos	Ref	Clos	Ref	Clos	Ref	Clos	Ref	Clos	Ref	Clos	Ref	Clos	Ref	Clos
Not receiving public assistance	70.4	80.2	70.6	81.8	88.8	96.3	96.0	99.2	92.0	97.3	94.1	96.6	95.4	98.4	95.9	98.8
Aid to the Blind	13.7	17.9	11.7	14.5	0.9	2.0	0.0	0.0	0.1	0.3	0.0	0.1	0.0	0.0	0.0	0.0
Aid to Permanently and Totally Disabled	0.4	0.0	0.3	0.3	0.7	0.2	0.1	0.0	0.2	0.1	1.5	1.1	0.4	0.1	0.2	0.2
AFDC only	1.3	0.8	2.0	0.7	2.2	0.7	1.8	0.7	4.1	1.7	2.3	0.7	1.6	0.2	2.2	0.7
General Assistance only	0.4	0.0	0.6	0.1	0.4	0.2	0.2	0.0	1.0	0.4	0.4	0.1	0.4	0.1	0.3	0.1
AFDC in combination with other types	0.4	0.4	0.3	0.7	0.4	0.4	0.1	0.0	0.6	0.1	0.2	0.0	0.3	0.0	0.2	0.0
Type unknown	13.3	0.0	14.3	0.0	6.5	0.0	1.7	0.0	1.9	0.0	1.4	0.1	1.9	0.0	1.1	0.0
Public assistance received between VR referral and closure only	N.A.	0.4	N.A.	1.7	N.A.	0.2	N.A.	0.0	N.A.	0.0	N.A.	1.2	N.A.	1.2	N.A.	0.1

SOURCE: Rand analysis of FY 1970 "Case Service Reports."

NOTE: Ref = time of referral; Clos = time of closure; N.A. = not applicable.

closure and 4 percent were in a state-agency-managed business enterprise (comparable figures for deaf youth unable to talk are 4 percent and 0 percent, respectively).

Average reported weekly earnings for hearing and vision handicapped youth were \$8 at referral, and \$84 at closure. The highest average earnings at closure, \$93, were for youth with one good eye. (See Table 9.17, for details). Note that average earnings across the various types of handicaps are fairly constant, from \$5 to \$10 per week at referral, and from \$80 to \$93 at closure. Figure 9.1 portrays the distribution of earnings at closure in relation to the 1970 national "minimum wage" of \$1.60 per hour. Only about two-thirds of the rehabilitated youth earned more than \$64, the minimum wage for a 40-hour workweek, and less than 20 percent earned over \$100 per week. In comparison, the median May 1970 weekly earnings of salaried

Table 9.16

PERCENTAGES OF REHABILITATED YOUTH IN VARIOUS WORK STATUS CATEGORIES, FY 1970 CLOSURES

Work Status Category	Blind		Partially Sighted: Legally Blind		Partially Sighted: 20/70 up to 20/200 Acuity		One Good Eye		Other Visual Impairment		Deaf, Unable to Talk		Deaf, Able to Talk		Other Hearing Impairment		All Types of Sensorial Impairment	
	Ref	Clos	Ref	Clos	Ref	Clos	Ref	Clos	Ref	Clos	Ref	Clos	Ref	Clos	Ref	Clos	Ref	Clos
	Competitive labor market	5.0	57.8	8.8	66.7	10.8	86.8	13.6	92.7	14.6	91.1	8.2	88.1	12.9	90.0	14.6	90.0	11.9
Sheltered workshop	2.9	20.5	0.9	13.4	0.9	3.1	0.0	0.5	0.5	1.2	0.5	4.2	0.4	1.4	0.1	0.9	0.4	3.2
Self-employed	0.0	3.1	0.1	2.4	0.2	1.8	0.1	1.2	0.2	0.5	0.3	0.7	0.2	1.0	0.1	0.9	0.2	1.1
State-agency-managed business enterprise	0.0	3.1	0.5	5.0	0.0	0.7	0.0	0.1	0.0	0.2	0.0	0.0	0.1	0.0	0.0	0.0	0.1	0.7
Homemaker	2.1	11.6	2.1	10.9	3.3	7.4	0.7	4.5	1.0	6.0	1.0	6.1	0.7	6.9	1.2	6.9	1.2	7.9
Unpaid family worker	0.0	3.9	0.9	1.5	1.3	0.2	0.3	1.1	0.8	0.8	0.4	0.9	0.5	0.8	0.6	1.4	0.6	1.1
Not working, student	49.6	0.0	47.2	0.0	53.8	0.0	56.1	0.0	49.7	0.0	59.9	0.0	53.9	0.0	51.9	0.0	53.5	0.0
Not working, other	39.1	0.0	39.2	0.0	29.4	0.0	28.8	0.0	29.0	0.0	29.4	0.0	30.7	0.0	31.1	0.0	31.2	0.0
Trainee or worker (noncompetitive labor market)	1.3	0.0	0.2	0.0	0.2	0.0	0.4	0.0	4.1	0.0	0.3	0.0	0.5	0.0	0.3	0.0	1.2	0.0

SOURCE: Rand analysis of FY 1970 "Case Service Reports."
 NOTE: Columns may not total exactly to 100 due to rounding. Ref = time of referral; Clos = time of closure.

Table 9.17

PERCENTAGES OF REHABILITATIONS IN VARIOUS WEEKLY EARNINGS RANGES, FY 1970 CLOSURES

Earnings (\$)	Blind		Partially Sighted: Legally Blind		Partially Sighted: 20/70 up to 20/200 Acuity		One Good Eye		Other Visual Impairment		Deaf, Unable to Talk		Deaf, Able to Talk		Other Hearing Impairment		All Types of Sensorial Impairment	
	Ref	Clos	Ref	Clos	Ref	Clos	Ref	Clos	Ref	Clos	Ref	Clos	Ref	Clos	Ref	Clos	Ref	Clos
	150 and up	11.0	5.7	5.3	4.7	2.4	6.2	0.8	6.0	1.2	3.9	2.2	2.3	2.6	3.5	0.9	4.4	2.1
100-149	0.8	16.4	0.9	11.7	0.4	16.7	0.5	25.1	0.5	15.9	0.5	15.7	0.8	18.8	0.8	18.7	0.6	18.4
60-99	2.7	35.1	4.1	40.9	4.4	48.5	4.9	47.3	4.4	47.9	3.4	56.9	4.4	53.3	5.4	48.7	4.5	48.4
40-59	1.9	11.5	1.3	14.6	2.9	12.6	3.5	9.8	6.2	15.2	2.5	10.2	3.9	9.5	4.9	12.3	4.0	12.0
20-39	0.4	9.2	1.4	9.9	2.0	5.9	3.5	4.2	4.7	7.2	1.4	5.1	2.6	5.4	3.2	6.2	3.0	6.2
0-19	83.3	22.1	86.9	18.1	87.9	10.1	86.8	7.7	83.0	9.8	90.0	9.7	85.7	9.5	84.9	9.7	85.8	10.5
Average	\$ 5	\$80	\$ 6	\$75	\$ 7	\$86	\$ 8	\$93	\$10	\$80	\$ 6	\$81	\$ 8	\$85	\$10	\$85	\$ 8	\$84

SOURCE: Rand analysis of FY 1970 "Case Service Reports."
 NOTE: Ref = time of referral; Clos = time of closure.

workers aged 16 to 24 were \$88 and \$112 for females and males, respectively. The low level of earnings at referral is not due simply to the young age of the clients, since the average earnings at time of referral for VR rehabilitants of all ages was only \$14 per week.

Services Provided to Youth

In addition to services such as vocational planning, counseling, and job placement which VR clients receive from the state agencies' rehabilitation counselors, agencies may purchase other services for clients. As shown in Table 9.18, nearly all sensorially impaired clients receive professional diagnostic and evaluation services to determine eligibility and the scope of other services needed. Nearly half of the rehabilitated youth received medical or medically related restorative services, and over three-quarters received vocational training. About one-third of the rehabilitants received income maintenance while participating in the VR program, and 30

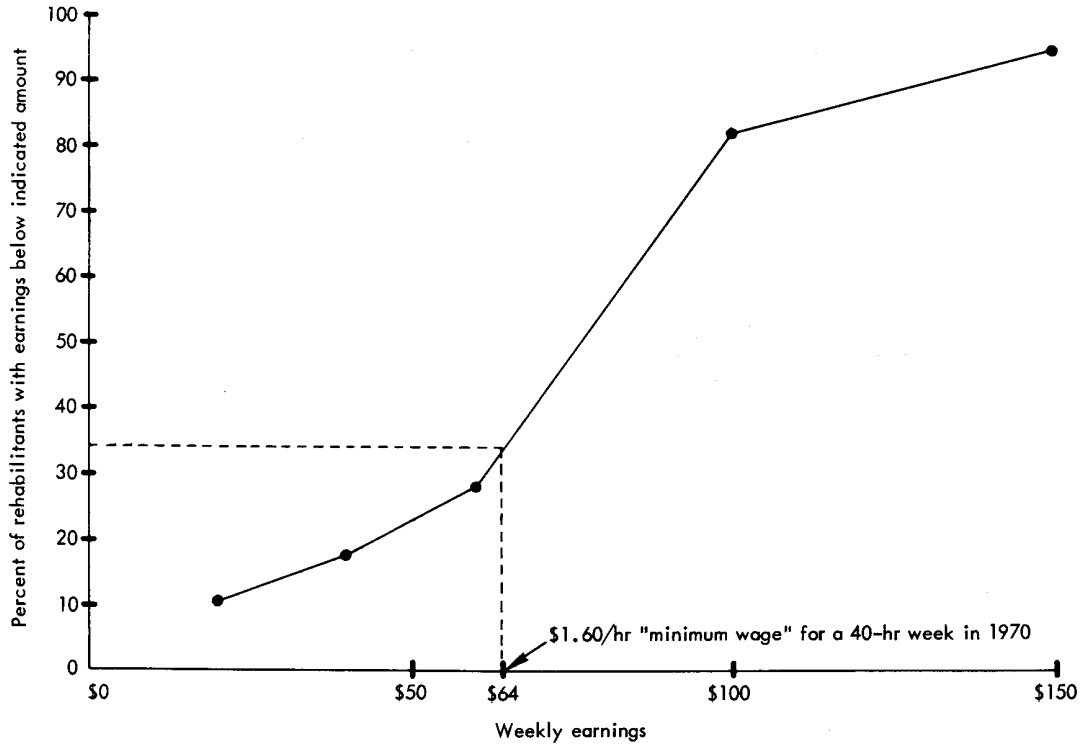


Fig. 9.1—Weekly earnings at time of case closure

Table 9.18

PERCENTAGES OF YOUNG VR CLIENTS RECEIVING VARIOUS TYPES OF SERVICES, FY 1970 CLOSURES

Type and Degree of Sensorial Handicap	Diagnosis and Evaluation		Restoration		Training		Income Maintenance		Services to Other Family Members		Other Services	
	Not Rehab	Rehab	Not Rehab	Rehab	Not Rehab	Rehab	Not Rehab	Rehab	Not Rehab	Rehab	Not Rehab	Rehab
Blind	95	93	31	33	95	85	44	57	3	7	53	60
Partially sighted--legally blind	89	91	15	37	57	81	23	49	1	2	33	40
Partially sighted--20/70 up to 20/200 acuity	100	95	24	31	61	82	25	42	0	1	25	35
One good eye	93	96	17	31	40	77	19	30	0	1	13	22
Other visual impairment	94	96	33	64	40	65	7	27	2	2	14	24
Deaf, unable to talk	94	97	22	35	63	83	19	36	3	9	30	44
Deaf, able to talk	98	96	37	53	54	78	31	30	4	5	22	33
Other hearing impairment	98	96	24	57	32	70	8	30	3	3	13	24
All types combined	96	96	25	47	47	76	18	34	2	3	20	30

SOURCE: Rand analysis of FY 1970 "Case Service Reports."

percent received other services such as reader or interpreter services, occupational tools and equipment, initial stocks, licenses, or transportation. Except for medically related restorative and diagnostic services, the more severe the disability, the more likely a rehabilitant was to have received each service.

Time Spent in Program

The average time between referral and acceptance for service for hearing and vision handicapped youth rehabilitants is 6 months, and between acceptance and closure is 19 months, for a total of 25 months. Clients who received training spent an average of 17 months in the training phase of the program alone. Clients who were not successfully rehabilitated spent nearly as long from referral to case closure, an average of 24 months. (See Table 9.19.) For comparison, the average time from referral to case closure for all physically or mentally handicapped youth was 21 months, and for all clients of all ages, 19 months.

Table 9.19

TIME SPENT IN VR PROGRAM, FY 1970 CLOSURES

Type and Degree of Sensorial Handicap	Average Months from Referral to Acceptance		Average Months In Training ^a		Average Months from Time "Ready for Employment" to Closure ^b		Average Months from Acceptance to Closure	
	Not Rehab	Rehab	Not Rehab	Rehab	Not Rehab	Rehab	Not Rehab	Rehab
Blind	6	9	14	16	15	6	21	22
Partially sighted--legally blind	8	8	14	16	12	5	19	18
Partially sighted--20/70 up to 20/200 acuity	6	7	15	17	8	5	19	22
One good eye	5	5	15	19	9	5	17	21
Other visual impairment	5	5	14	16	9	4	17	16
Deaf, unable to talk	8	7	12	14	13	5	20	19
Deaf, able to talk	6	6	12	16	11	6	19	20
Other hearing impairment	5	5	14	17	11	5	16	19
All types combined	6	6	14	17	11	5	18	19

SOURCE: Rand analysis of FY 1970 "Case Service Reports."

^aFor those who received training only.

^bFor those who reached the state of being "ready for employment only."

Expenditures for VR for Hearing and Vision Handicapped Youth, FY 1970

Estimated expenditures for hearing and vision handicapped youth under the basic state-federal VR program in FY 1970 were \$20,408,000. Of that amount, \$11,428,000 was for the "cost of services" and the remainder was for the cost of state counselors and for operation of the state agency.¹³

¹³ Assuming, for lack of better data, that all expenditures are distributed by type of handicap in the same proportions as "cost-of-services" expenditures are distributed by type of handicap.

Average total expenditures per youth accepted were \$1765, while expenditures per youth successfully rehabilitated were \$2103. Expenditures per rehabilitant decreased with degree of severity, from \$6167 for a blind youth to \$1362 for a youth with "other visual impairment," and from \$2068 for a deaf youth unable to talk to \$1678 for a youth with "other hearing impairment." Note that three times as much is expended per blind youth as is expended per deaf youth who is unable to talk. (Table 9.20 provides details.)

The extremely wide variation in the cost of services by handicap and by state is shown in Table 9.21. For example, the 1970 average costs of services (which are slightly more than half of total expenditures) per blind youth rehabilitated averaged \$3227 in the United States, but 5 states averaged less than \$1000, while 8 states averaged more than \$6000. Average expenditures per young rehabilitant with one good eye varied across states from less than \$100 to more than \$3000. The U.S. average per young deaf rehabilitant unable to talk was \$1081, but 4 states averaged under \$200 and 6 states averaged over \$2000.

Table 9.20
ESTIMATED BASIC STATE-FEDERAL VR PROGRAM EXPENDITURES FOR YOUTH
BY DISABILITY GROUP, FY 1970 CLOSURES

Type and Degree of Sensorial Handicap	Total Cost of Services (000)	Estimated Total Expenditures ^a (000)	Average Total Expenditures per Youth		Percent of Expenditures Incurred by Handicap Group	Average Cost of Services per Youth		
			Accepted	Rehab		Not Accepted	Accepted	Rehab
Blind	\$ 908	\$ 1,622	\$4,771	\$6,167	8.0	\$31	\$2,796	\$3,227
Partially sighted--legally blind	2,395	4,277	3,365	4,303	21.0	27	1,927	2,179
Partially sighted--20/70 up to 20/200 acuity	586	1,046	1,916	2,299	5.1	24	1,335	1,269
One good eye	2,059	3,677	1,465	1,693	18.0	10	847	939
Other visual impairment	1,548	2,764	1,164	1,362	13.5	13	658	722
Deaf, unable to talk	1,084	1,936	1,607	2,068	9.5	17	941	1,081
Deaf, able to talk	1,224	2,186	1,651	1,941	10.7	15	958	1,048
Other hearing impairment	1,624	2,900	1,454	1,678	14.2	14	824	910
Total	\$11,428	\$20,408	\$1,765	\$2,103	100.0	\$15	\$1,024	\$1,120

SOURCE: Rand analysis of FY 1970 "Case Service Reports."

^aAssumes that the U.S. average of 56 percent of total expenditures on "services to individuals" holds for each group of handicapped youth. Only 1 percent of the youth accepted into the VR programs are eligible to have the Social Security Trust Fund pay costs. These costs are included in the totals presented.

COMMITTEES ON EMPLOYMENT OF THE HANDICAPPED

The Presidential Committee on Employment of the Handicapped, the corresponding Governors' Committees on Employment of the Handicapped in the 50 states, and hundreds of local committees promote employment opportunities for the mentally and physically impaired. Primarily, these committees endeavor to educate potential employers and the public regarding the vocational abilities of the handicapped, rather than provide individual placement services. Many of the committees are also active in backing legislation to remove barriers to employment of the handicapped, including physical obstacles in architecture and transportation.

The FY 1972 budget estimate for the Presidential Committee was \$726,000 for persons of all ages. Since approximately 21 percent of the U.S. population who have some chronic physical or mental condition that may limit their activities are under

Table 9.21

AVERAGE COST OF SERVICES PER YOUTH SUCCESSFULLY REHABILITATED,
BY STATE, FY 1970 CLOSURES^a

(In \$)

U.S. Figures/ State Figures	Type and Degree of Sensorial Impairment							
	Blind	Partially Sighted-- Legally Blind	Partially Sighted-- 20/70 up to 20/200 Acuity	One Good Eye	Other Visual Impair- ment	Deaf, Unable To Talk	Deaf, Able To Talk	Other Hearing Impair- ment
United States	3227	2179	1269	939	722	1081	1048	910
Alabama	4398	4034	1339	756	341	2892	1750	1273
Alaska	--	3693	32	168	255	--	1553	3348
Arizona ^b	758	3548	--	43	48	2218	2619	1782
Arkansas ^b	1951	2057	237	1475	610	1538	1082	859
California	2849	1066	755	400	642	561	817	484
Colorado	2128	1099	1181	1032	656	967	1606	816
Connecticut ^b	4380	1545	--	141	2136	3317	1150	1579
Delaware ^b	--	3954	2871	483	482	--	1369	1610
D.C.	7708	511	--	124	126	1798	518	99
Florida ^b	5020	1935	5122	526	389	1168	791	820
Georgia	1371	1262	671	867	882	370	752	1164
Hawaii	562	1599	2230	1890	67	308	701	477
Idaho ^b	--	940	1333	617	279	256	852	482
Illinois	1610	1437	1677	915	922	1073	1629	1478
Indiana ^b	2188	1972	903	729	1034	736	605	899
Iowa ^b	3489	5274	547	760	301	1083	670	594
Kansas ^b	6379	3721	716	1298	1212	1547	768	467
Kentucky	4589	1150	848	535	333	576	406	764
Louisiana ^b	940	1972	691	967	1334	173	1663	883
Maine ^b	--	6866	--	3319	1158	2277	1165	--
Maryland	440	428	255	261	99	675	502	389
Massachusetts ^b	12915	2543	1767	2034	1724	655	862	1031
Michigan ^b	1575	1871	361	593	463	874	535	614
Minnesota ^b	5332	3104	1129	1367	2321	132	224	682
Mississippi ^b	6828	2212	1670	1249	973	182	1079	1102
Missouri ^b	5237	2215	1662	1221	693	1303	1006	1162
Montana ^b	5270	1364	4172	900	707	865	587	509
Nebraska ^b	6412	1655	920	1171	1621	1810	1131	543
Nevada ^b	--	--	--	--	65	801	249	231
New Hampshire ^b	--	1799	1792	1922	23	--	1200	999
New Jersey	(c)	(c)	(c)	(c)	(c)	(c)	(c)	(c)
New Mexico ^b	2872	984	999	176	964	533	1011	480
New York ^b	3114	2917	1196	1845	1949	1497	1843	1634
North Carolina ^b	7764	5382	1480	1226	927	582	558	514
North Dakota	6758	2388	--	1204	1140	1165	1027	809
Ohio ^b	2509	2262	1778	1097	496	534	999	1114
Oklahoma	2926	1350	618	867	683	352	958	671
Oregon ^b	4408	1825	1308	505	365	467	220	233
Pennsylvania ^b	4766	2563	1044	1369	687	1752	1734	1093
Rhode Island ^b	5444	3734	1649	817	393	995	1523	600
South Carolina ^b	--	130	1213	906	365	617	686	568
South Dakota ^b	1049	3824	6015	982	3320	912	514	1343
Tennessee ^b	6119	2267	989	1016	924	789	472	996
Texas ^b	2846	1159	1242	477	480	767	912	650
Utah	4567	1651	649	447	451	1566	341	443
Vermont ^b	--	--	--	115	--	109	790	845
Virginia ^b	508	1220	242	654	562	1156	712	581
Washington ^b	7506	2350	--	589	875	1932	815	505
West Virginia	3430	1958	815	1330	574	2422	1759	610
Wisconsin	1693	2188	1499	769	737	3123	2252	746
Wyoming	--	--	1073	81	1190	--	2331	563

^a Data presented on persons under age 22 have been computed at The Rand Corporation from FY 1970 "Case Service Reports," DHEW form RSA-300, submitted on each individual applicant at the time of case closure. The average presented is the total cost of services to successful rehabilitants divided by the number of successful rehabilitants.

^b In 1970, state had a separate VR agency for the visually handicapped, in addition to one for all other handicaps combined.

^c Not available.

age 22,¹⁴ we estimate that 21 percent of the \$726,000 budget, or \$152,000, goes to handicapped youth. Governors' Committee budgets and staffs are small. The Massachusetts Committee, for example, runs on \$450 annually with two staff members loaned from the state employment service. Illinois is exceptional, with a relatively high annual budget of \$146,000.¹⁵ At these still low levels of expenditure, the committees cannot develop an extensive, high-quality set of public and employer education material; nor can they fund extensive campaigns in the media.

FEDERAL EMPLOYMENT OF THE HANDICAPPED

The Civil Service Commission provides assistance to handicapped persons seeking federal employment. Budget obligations in FY 1970 and FY 1972 were \$70,000 and \$72,000, respectively.¹⁶

THE RANDOLPH-SHEPPARD VENDING STAND PROGRAM

In FY 1971 a total of 3454 blind and visually handicapped persons operated vending stands in governmental buildings and earned an average of \$6540 each from the businesses.¹⁷ It is assumed that only a small fraction of the operators are under 21.

EMPLOYMENT SERVICES

In FY 1970 the federal government budgeted \$348 million for grants to states for employment services, including interviewing, counseling, and job placement referrals for individuals. This amount averaged \$35 for each of the 9,957,000 applicants for services in that year. The objective of these services is not vocational rehabilitation, but the matching of potential employees with employers. Special attention reportedly is given to the physically and mentally handicapped and other disadvantaged groups.

The total nonagricultural placements of handicapped persons of all ages in the United States in FY 1969 by the Employment Service program were 324,000; and that number grew about 22,900 from 1966 to 1969.¹⁸ The data from this program are not extensive, and the number of hearing and vision handicapped youth served is not reliably known. Our estimate of over 11,000 in 1970 is based on the assumption that the age breakdown of state employment service expenditures for handicapped persons is similar to that in the VR program.

Difficulties with the Employment Service program were noted in the *1973 Manpower Report of the President*: "... with the ES caught in an avalanche of new

¹⁴ U.S. Department of Health, Education and Welfare, *Limitation of Activity and Mobility Due to Chronic Conditions, United States, July 1965-June 1966*, National Center for Health Statistics, PHS Publication No. 1000, Series 10, No. 45.

¹⁵ Financial data from staff members of the Illinois and Massachusetts Governors' Committees on Employment for the Handicapped.

¹⁶ *Catalog of Federal Domestic Assistance*, Executive Office of the President, Office of Management and Budget, 1972.

¹⁷ U.S. Department of Health, Education and Welfare, *Justification of Appropriation Estimates for Committee on Appropriations—FY 1973*, Vol. VI.

¹⁸ Data from Manpower Administration, U.S. Department of Labor, Washington, D.C.

responsibilities, its effectiveness—as measured by the number of job placements made—has declined sharply in recent years. . . . Between 1966 and 1970 . . . ES non-farm placements dropped 30 percent . . . contacts with employers dropped 20 percent . . . accompanied by a decline of one-third in the number of job openings obtained. . . . The number of placements of disadvantaged workers also fell.”¹⁹

During our five-state interviews with VR and employment service personnel,²⁰ several observations on the employment service program were made which, if accurate, bear further investigation: (1) information on each job and client were said to be generally insufficient to permit effective matching of the handicapped client’s abilities with job requirements; (2) employment service personnel were said to have such high client loads in most states that they often were unable to provide good placement service to handicapped persons; and (3) specialists in serving handicapped persons were said to be insufficient in number, with the result that personnel without special training often served handicapped persons.

BENEFIT-COST ANALYSIS OF VOCATIONAL SERVICES FOR HEARING AND VISION HANDICAPPED YOUTH

Previous studies have concluded that the VR program for handicapped persons has yielded benefits that considerably outweigh the cost of the program. For example, a 1967 study by the U.S. Vocational Rehabilitation Administration found that each dollar of cost in FY 1966 generated an estimated \$35 in increased clients’ earnings and value of work activity over their working lives.²¹

A more thorough study, using more conservative assumptions, has been made by Ronald W. Conley.²² His analysis of the VR program focuses on economic costs and benefits, makes sophisticated use of available data, and clearly states the assumptions used in making estimates. With 1967 data, Conley estimates that for each dollar of the social cost of rehabilitation services, an increase in lifetime earnings of a little less than \$5 accrues (at a 4-percent discount rate on future increased earnings). He also estimates that “the increased taxes paid by the rehabilitants and the reduction in tax supported payments for their maintenance amount to perhaps as much as 25 percent of the total increase in earnings.” Critical assumptions underlying these and all other estimates relate to how one estimates what earnings would have been without rehabilitation, and what the employment record of the rehabilitant will be over his lifetime.

In the following analysis, we will use Conley’s methodology, with some significant adaptations. First, previous analyses have generally dealt with the program as a whole, not with disaggregations by type and degree of handicap and by age of the recipient. We will investigate the program’s costs and benefits for eight categories of hearing and vision handicapped youth, and will also look at differences based on sex and race. Second, although the data for the VR program are generally better

¹⁹ U.S. Department of Labor, Washington, D.C., March 1973, pp. 31, 47.

²⁰ 1972 interviews with VR personnel in Arkansas, California, Illinois, Massachusetts, and Wyoming, and with ES personnel in Massachusetts and Illinois.

²¹ U.S. Department of Health, Education and Welfare, Vocational Rehabilitation Administration, *An Exploratory Cost-Benefits Analysis of Vocational Rehabilitation*, Washington, D.C., August 1967.

²² *The Economics of Vocational Rehabilitation*, Johns Hopkins University Press, Baltimore, Maryland, 1965; and see idem, “A Benefit-Cost Analysis of the Vocational Rehabilitation Program,” *The Journal of Human Resources*, Vol. 4, No. 2, April 1969, for one of the best of these benefit-cost studies and a review of others. See also Rand Report R-1220-HEW, Chapter 5, for citations of other recent and ongoing analyses.

than data for any other program we investigated, benefit-cost analyses must still resort to assumptions where data are incomplete. We will vary certain of those assumptions and note the sensitivity of estimated benefits to the variations.

The analyses in the remainder of this section will concentrate on economic benefits, which are only one of the various types of benefits on which this program can be evaluated. Earlier in this chapter we presented available data on other classes of criteria, such as degree of change in nondependence and equity of service distribution. Data are not available for one of the most significant classes of effects, changes in the overall quality of life of youth served. As will be seen, the VR program appears justified by its economic benefits alone. Other unquantified but very significant major types of benefits add still more support for this program.

Benefit-Cost Methodology

For a more detailed description of the methodology we are using with certain adaptations, the reader is referred to Conley's works.²³ The methodology is briefly discussed here to lay out its underlying assumptions. We first describe components of cost, and then discuss the calculation of economic benefits.

Basic Program Costs. The basic program costs include those of administration, vocational counselors, case services,²⁴ and the establishment and support of rehabilitation facilities and workshops. When considering the effectiveness of the total program, it is possible to use the budget as an indicator of the program cost. However, if we want to make distinctions among the various groups participating in the program, we must try to disaggregate the cost. The only expenditure that is kept in a client's file is that for case services, such as medical diagnostics, treatment, or vocational training. The other costs are generally treated as "overhead" and are not attributed directly to individual clients by the agency. To do an analysis by handicap, race, age, or sex, we must devise some means of allocating overhead costs to each type of client. Two possible methods of allocation suggest themselves. First, those "overhead" costs could be attributed on a per capita basis. This would be an accurate approximation if these services (e.g., counseling and guidance) were independent of the length and cost of the service program that is designed to help the client. Another approach, and the one adopted for this analysis, is to allocate all costs in proportion to the amount of cost of case services for the individual clients.²⁵ This implies that the types of clients who receive the most in case services, such as medical treatment and training, also consume a higher proportionate share of counseling and other expenditures. Because high service costs are likely to be associated with the most difficult cases, such an allocation scheme is not unreasonable. Some clients, however, have no "cost of case services," and are successfully rehabilitated with, for example, only counseling and placement services from VR agency personnel. The assumption of allocating all costs in relationship with case service costs would imply that these types of clients were served at no cost. However, since those who have zero cost of case service are only a small fraction of the total, and are distributed across all handicap types, the resultant error is likely to be small.

Maintenance Cost. The cost of income maintenance payments is not counted as a cost to society in the benefit-cost analysis. This stems from the fact that the cost to the group that pays the income transfer payment is equal to the benefits that accrue to the recipients of the income transfer payment; cost and benefits of the

²³ Conley, *The Economics of Vocational Rehabilitation*, and idem, "A Benefit-Cost Analysis."

²⁴ Called "Cost of Services" in the preceding section.

²⁵ In 1970 the ratio of basic program costs to the cost of case services was approximately 1.78. See Chapter 5 of R-1220-HEW for details of the components of each of these two types of cost.

transfer cancel each other out when society as a whole is considered. This is not to say that they are cancelled out if we are considering any group *within* society, such as taxpayers. In the case of taxpayers, income maintenance costs would be considered because most recipients of the income transfer payments are not representative taxpayers. Conley estimates that approximately 7 percent of the program cost goes for income maintenance. It was not possible to get a better estimate of the actual amount of program funds going for maintenance for hearing and vision handicapped youth. We therefore adopted Conley's figure.

Adjustment for Carryovers. The VR program has been growing steadily over the past decade. If the total annual expenditures were divided by the number of successful rehabilitations in a given year to obtain an average unit cost, the estimate would be biased upward because most clients are served more than one year. To adjust for this bias, Conley reduced the estimate of program cost by 2 percent. Our cost data are in a somewhat different form from Conley's. We have the cost of case services for all FY 1970 closures. Therefore, we do not have cost data on persons who entered the program but were not closed in 1970. However, the overhead rate used here would be biased upward slightly. Because of the growth in the program, a downward adjustment of 2 percent of the basic program cost is made.

Other-Party Costs. Some clients receive services that are not financed by the VR agency and hence do not show up in the budget of the agency or in the expenditure record of the client. Conley has estimated that such expenditures amounted to 4 percent of the annual program costs, and we use this estimate.

Repeater Costs. Some of the clients in the program have previously received service from the VR agencies. Others, especially youth, will receive additional service in the future. Conley argues that both these past and future costs should be included as part of the incremental social costs for the current year's rehabilitants. Since Conley's data indicated that 22 percent of the year's rehabilitants were or would become rehabilitation "repeaters," and assuming that future service costs are the same as the present average cost of rehabilitation, the program cost should be increased by approximately 22 percent to account for these "repeat" costs.

It is important to count program costs in benefit-cost analysis if in fact the benefits from these expenditures are also measured. It is not clear, from the methodology presented later for estimating benefits, that the benefits from past and future VR expenditures on a single client are incorporated into Conley's model. For example, past expenditures should be reflected in the income that the client has been receiving. Since the client's income upon entering the program is subtracted from his future income to obtain an estimate of net benefits, benefits flowing from past expenditures do not appear to be included in Conley's analysis. Conley's methodology on repeaters will be used in the base case.

Research, Training, and Construction Costs. This year's clients are also recipients of the benefits of previous research, staff training, and past expenditures on construction of facilities. These costs must be amortized to get an estimate of the program's true cost. Conley found that public expenditures for these categories were about 20 percent of the annual basic program cost, and that private support in these categories was about 5 percent of basic program cost. This meant that an estimate of the cost of research, training, and construction programs that could be allocated to this year's program would be equal to 25 percent of this year's basic program cost.

Opportunity Cost. One of the social costs of the VR program is the opportunity cost associated with the production that is lost when the client forgoes the labor force and enters the program. Conley estimates this production loss as equal to 35 percent of the first year's earnings of the successful rehabilitants after they leave the program. He estimates

forgone earnings [based] on the earnings reported by rehabilitants during the three months prior to acceptance (1962-64). These earnings averaged around 40 percent of those at closure, and given that it requires 85 percent of a year to complete rehabilitation, then forgone earnings would be equal to about 35 percent of estimated annual earnings at closure.²⁶

Two features of his analysis appear questionable. First, he considers the forgone earnings only of those successfully rehabilitated. But unrehabilitated clients also had to forgo earnings—a small but real cost of the program that should be included. Second, since real data on earnings at acceptance were available, it would seem only reasonable to use those data instead of approximations. It is especially important to do so in our case because the ratio of the two earnings is not likely to hold constant among age groups. For totally blind or profoundly deaf youth, for example, this ratio is closer to 8 percent. Since the Conley methodology is being used in the base case, however, his methodology is adopted here and will be modified in the sensitivity analysis later in this section.

Benefits. We emphasize that the VR program produces several types of benefits for both the client and society. There are obvious psychic and other benefits to the client, notably self-sufficiency, but in this section we are concerned with the economic benefits that can be attributed to the services provided by the program.

Three major parameters must be specified to find the total increase in earnings from the VR program: the number of years the client will work, the differential in earnings for each year between what he earns after VR services and what he would have earned without them, and the discount rate. The specification or estimation of each parameter is discussed below.

Number of Years Worked. To estimate the number of years worked, Conley assumes that unless the rehabilitant suffers vocational failure or dies, he works until he retires at the age of 65. Conley's mortality rates are taken from experience with Railroad Retirement Disability annuitants. This group has high mortality rates compared with the population in general. Conley makes this conservative assumption noting that this is the "worst possible" case for the VR program. If the VR program is cost-beneficial under this assumption, it is even more beneficial under less stringent assumptions.²⁷ These mortality rates are very unrealistic for hearing and vision handicapped youth. Only 50 percent of those who are rehabilitated between the ages of 16 and 19 are assumed to live to be 40 years old. That figure soars to 96 percent if one uses 1959 mortality data for the general population.

A critical assumption concerns the amount of unemployment later in life. The number of years worked after rehabilitation and before reaching age 65 must be adjusted to reflect periods of possible unemployment. As described in the next section, Conley argues that the decrease in earnings due to unemployment is offset by the increase in productivity (as measured by earnings) of those who retain their employment.

Earnings Differential. Conley estimates the increase in productivity among successfully rehabilitated clients due to VR services as follows:

We will accept our conclusions from the follow-up studies that 80 percent of all rehabilitants are still gainfully employed five years after closure and that their average earnings are about 25 percent higher than the average earnings of rehabilitants in the year of closure, and we will further assume that these successful rehabilitants will continue to be employed at these higher

²⁶ Conley, "A Benefit-Cost Analysis," p. 241.

²⁷ This kind of analysis is termed *a fortiori*. It is explained in G. H. Fisher, *Cost Considerations in Systems Analysis*, Elsevier Publishing Co., New York, 1971.

wages until death or retirement. Given these assumptions, it follows that the increase in earnings due to rehabilitation during any time period after rehabilitation will vary with the number of rehabilitants still employed (since the loss of earnings among live rehabilitants of working age who fail to maintain their employment is offset by the increased earnings of successful rehabilitants). Total increased output due to rehabilitants will, therefore, be equal to the average number of years worked by rehabilitants still employed five years after closure multiplied by the increase in earnings between acceptance and closure.²⁸

A recent follow-up survey of 4146 VR service recipients in six states one, two, and three years after closure, conducted by National Analysts, Inc.,²⁹ suggests that the assumption about the percentage working five years after closure is too high. Our later sensitivity analysis accordingly considers what the economic benefits would be if the figure were less. The National Analysts report indicates that in the 12 months following closure, 47 percent of the rehabilitants worked without interruption, 29 percent did not work at all, and 57 percent were working for pay when interviewed. Comparable figures for nonrehabilitants were 19 percent, 60 percent, and 24 percent, respectively. Over a 36-month period following closure, the percentage employed for pay at the time of the interview decreased only slightly, to 55 percent. The average amount of time worked for pay averaged just over 7 months per year, but varied from about 6 months per year up to 9 months per year depending on sex and race. However, rehabilitants under age 30 fared better; approximately 67 and 77 percent of females and males, respectively, were working for pay at the time of the interview.

The National Analysts study also presents new data on the percentage increase in earnings one, two, and three years after closure. In constant-value dollars, mean monthly earnings of 0- to 24-year-old rehabilitants increased about 25 to 35 percent for males and 20 to 30 percent for females. For rehabilitants of all ages at the end of one, two, and three years, earnings increased 30, 32, and 32 percent, respectively. However, even if Conley's assumption of a 25-percent increase in earnings over a five-year period after rehabilitation is accurate, it may not be appropriate to label this as a benefit of the VR program. Employer-conducted or on-the-job training, not the VR program, may have increased the skills of the rehabilitants after the time of closure.

A large possible error, however, is introduced if it is assumed that the increase in output is equal to the difference in earnings at acceptance and at closure for the youth. Although this may be a justifiable assumption for those who have already been in the labor force, it loses credibility for those who enter the VR program before entering the labor force and sometimes before leaving school, and therefore have no earnings at acceptance.³⁰ It is difficult to believe that at least some of the less severely handicapped (e.g., those with 20/70 vision, or one good eye) could not qualify for jobs without VR training. Our doubts are strengthened by the National Analysts study, which found that 78 percent of the rehabilitants under age 30 thought they could have obtained their present positions without VR services.³¹ The sensitivity

²⁸ Conley, "A Benefit-Cost Analysis," pp. 234-235.

²⁹ National Analysts, Inc., *A Follow-Up Study of Closed Vocational Rehabilitation Cases, Final Report to the Social and Rehabilitation Service, U.S. Department of Health, Education and Welfare*, Contract No. SRS-69-54, April 1972.

³⁰ Only 12 percent of hearing and vision handicapped youth under age 22 were reported as working at acceptance. Over 50 percent were students when they were accepted into the program.

³¹ National Analysts, Inc., *op. cit.*, p. 194.

of the effectiveness of this program to various estimated changes in earnings is examined later.

Discounting. The total stream of benefits can now be estimated by multiplying the number of man-years of life by the assumed increase in earnings due to the VR program for each type of handicapped client. Given a preference, however, one would prefer earnings this year to the same amount of earnings at some distant time in the future. To account for that preference, future benefits must be discounted. Just what is the proper amount to discount future costs and benefits from government projects has been subject to extensive study and controversy. Rather than choose a single discount rate, we will use 4 percent in our base case analysis and examine some other values in the later section devoted to sensitivity analysis.

Benefit/Cost Analysis: Base Case

For the base case analysis, we will use Conley's methodology and the data on hearing and vision handicapped youth derived from the FY 1970 case closures described earlier in this chapter. The next section will test the sensitivity of the analysis to various other assumptions.

The relative costs of services per rehabilitant are shown in Table 9.22 by the type and degree of hearing and vision handicap and by race and sex. The corresponding benefit/cost ratios are shown in Table 9.23.

Looking at the relative cost for the different types of handicaps, note that the legally blind youth have relatively high costs compared with those for the less severely visually handicapped and the hearing handicapped. Because earnings at referral and closure are fairly similar for youth with each of these types of handicaps, cost differences account primarily for differences in the benefit/cost ratios by type of sensorial handicap. The average benefit/cost ratio for all these youth is 10.8 using Conley's methodology. The benefits returned per dollar of cost go up as severity of handicap goes down: from 11.0 for deaf youth unable to talk to 12.3 for hard of hearing youth, and from 4.3 for totally blind youth to 13.6 for youth with one good eye. Thus, using Conley's methodology for this base case analysis, the VR program appears to yield high economic benefits to society in relation to the cost of the services.

The cost per rehabilitant is about the same for the entire group of hearing and vision handicapped youth and for females only. Thus, the lower benefit/cost ratios shown for females are due to a lower average improvement in earnings from time of referral to closure. Much of this discrepancy can be explained by the facts that a lower percentage of women who are rehabilitated enter the paid labor force, as compared with the total population, and those who do earn less than the total population, on the average. Over 87 percent of rehabilitants of both sexes were working in the competitive labor market at the time of closure, but only 78 percent of the female successes were classified as working in that market. The estimated average weekly earnings of female successes at closure was \$13.70 less than the average for all hearing and vision handicapped youth rehabilitants.

It is seen that the average benefit/cost ratio for nonwhite youth is slightly higher than that for the total population. However, the costs of service to nonwhite youth were significantly lower, and average weekly earnings of nonwhite youth at the time of closure were also lower by \$7.30.

In summary, although it is clear that some types of handicapped youth do better than others in a benefit/cost sense, the program appears to offer society a handsome return on investment regardless of the type or degree of hearing or vision handicapped youth. This is in line with previous findings. As we vary some of Conley's

Table 9.22

RELATIVE COST OF SERVICES PER REHABILITANT BY TYPE
OF HEARING AND VISION HANDICAPPED YOUTH

Type and Degree of Sensorial Handicap	Cost as Percentage of the Average for All Types of Sensorially Handicapped Youth		
	Total Youth	Female Only	Nonwhite Only
Blind	293%	358%	253%
Partially sighted--legally blind	204	213	176
Partially sighted--20/70 up to 20/200 acuity	109	102	91
One good eye	80	88	67
Other visual impairment	65	54	82
Deaf, unable to talk	98	99	100
Deaf, able to talk	92	95	81
Other hearing impairment	80	79	78
All types combined	100%	102%	81%

Table 9.23

VR BENEFIT/COST RATIO BY TYPE OF HEARING AND VISION HANDICAPPED
YOUTH: BASE CASE METHODOLOGY

Type and Degree of Sensorial Handicap	Benefit/Cost Ratio for		
	Total Youth	Female Only	Nonwhite Only
Blind	4.3	3.2	4.6
Partially sighted--legally blind	5.5	4.2	5.5
Partially sighted--20/70 up to 20/200 acuity	10.4	8.7	10.9
One good eye	13.6	11.0	17.8
Other visual impairment	13.5	12.7	17.8
Deaf, unable to talk	11.0	9.8	10.2
Deaf, able to talk	11.4	9.9	11.3
Other hearing impairment	12.3	10.8	10.7
All types combined	10.8	9.0	11.2

assumptions, however, the success of the program appears to be somewhat less than the base case analysis indicates. We now turn to sensitivity analysis.

Benefit/Cost Analysis: Sensitivity to Data and Assumptions

This section explores the sensitivity of the conclusion that the VR program is highly cost-beneficial to those data and assumptions. Many different combinations of data and assumptions are possible. Our tactic here is to vary the most significant of them one at a time to isolate and study their influence, and then to make what appears to be a realistic set of changes of more than one type of data and assumption.

Discount Rate. The base case analysis used a discount rate of 4 percent. Its use assumes that the government or private enterprise does not have an investment

opportunity that yields over 4 percent. While it is impossible to say what the correct discount rate is, since conditions in the future will change that rate, we can measure the effects of various discount rates on our conclusions. Table 9.24 presents the benefit/cost ratio associated with various discount rates from 4 to 10 percent. It is seen that even for the relatively high discount rate of 10 percent, the program is still returning positive benefits relative to its cost (i.e., the benefit/cost ratio is greater than one) for all eight categories of handicapped youth studied.

Cost. Several of the data and assumptions about cost can be debated. However, for any reasonable changes in the cost used, the conclusion that the program is cost-beneficial does not change. For example, if the cost goes down, the benefit/cost ratio goes up. On the other hand, if the cost goes up by, say, 25 percent, the benefit/cost ratio is reduced by only 20 percent and is still high.

Number of Rehabilitants Who Continue To Work. The base case analysis assumes an extremely high mortality rate for these youth and still shows the program to be cost-beneficial. We will not use a still higher mortality rate because it appears perhaps unreasonably high already. The base case analysis also assumes that 80 percent of those with earnings at closure have earnings 5 years from closure, and later earnings increases from employed rehabilitants offset later increases in unemployment. If no change is made in the assumptions about the earnings of those who remain employed, total benefits decline as the 80 percent employment figure is lowered; the benefit/cost ratios in Table 9.25 are obtained for various assumptions about the percentage that stays in the labor force after five years. As the table indicates, the benefits exceed the cost (ratio exceeds 1.0) for even the most severely handicapped youth, even if only 20 percent retain full-time employment. Since no follow-up study on rehabilitants we are aware of has concluded that the rate of employment after successful rehabilitation is that low, the VR program for sensorially handicapped youth appears to be cost-beneficial for all reasonable values of employment rate, if all other assumptions remain unchanged.

Earnings Gain Due To VR Services. A major assumption in the base case analysis was that the earnings gain due to VR services was equal to the difference between reported earnings at time of referral and at closure. However, the assumption that earnings at referral were a good indication of what the client would continue to earn in the absence of the VR program is open to serious question. It is difficult to get an accurate estimate of what would happen to those clients if the VR program did not exist since accurate data on earnings of hearing and vision handicapped persons in the general population do not exist and because the VR program clients probably are not typical of that population.

Rather than trying to get a more accurate estimate of earnings without VR services, we use several different earnings assumptions to get an idea of their effects on the base case analysis benefits. Table 9.26 shows the benefit/cost ratio of the VR program under four different assumptions about earnings without services. It is assumed that 25, 50, 75, and 100 percent of those cases closed as successes would have been employed, with the average earnings equal to the 1970 minimum wage, in the absence of VR services (i.e., a minimal \$64 a week on the average).

According to the table, even if 100 percent of the rehabilitants could obtain minimum wage jobs on the average without training, the program would be slightly cost-beneficial for the entire client population of hearing and vision handicapped youth, but would not be cost-beneficial for profoundly deaf or legally blind youth. (Where the benefit/cost ratio shown is negative, the VR program is less effective in earnings terms than a program that puts 100 percent of the rehabilitants in minimum wage jobs.)

Within all the categories from the more severely to the less severely disabled,

Table 9.24

VR BENEFIT/COST RATIO BY TYPE OF HEARING
AND VISION HANDICAPPED YOUTH:
SENSITIVITY TO DISCOUNT RATE

Type and Degree of Sensorial Handicap	Benefit/Cost Ratio with Discount Rate of:			
	4%	6%	8%	10%
Blind	4.3	3.5	2.8	2.4
Partially sighted--legally blind	5.5	4.4	3.6	3.1
Partially sighted--20/70 up to 20/200 acuity	10.5	8.3	6.8	5.8
One good eye	13.6	10.8	8.9	7.5
Other visual impairment	13.5	10.7	8.8	7.4
Deaf, unable to talk	11.0	8.7	7.2	6.1
Deaf, able to talk	11.4	9.1	7.5	6.3
Other hearing impairment	12.3	9.8	8.1	6.8
All types combined	10.8	8.6	7.1	6.0

Table 9.25

VR BENEFIT/COST RATIO BY TYPE OF HEARING AND
VISION HANDICAPPED YOUTH: SENSITIVITY
TO RATE OF EMPLOYMENT

Type and Degree of Sensorial Handicap	Benefit/Cost Ratio with Employment Rate After 5 Years of:			
	80%	60%	40%	20%
Blind	4.3	3.2	2.2	1.1
Partially sighted--legally blind	5.5	4.1	2.8	1.4
Partially sighted--20/70 up to 20/200 acuity	10.4	7.8	5.2	2.6
One good eye	13.6	10.2	6.8	3.4
Other visual impairment	13.5	10.1	6.8	3.4
Deaf, unable to talk	11.0	8.3	5.5	2.8
Deaf, able to talk	11.4	8.6	5.7	2.9
Other hearing impairment	12.3	9.3	6.2	3.1
All types combined	10.8	8.1	5.4	2.7

the VR program has economic benefits that exceed its costs even if 75 percent or less earn the minimum wage in the absence of the program.

In the base case analysis that took earnings at time of acceptance as a measure of income in the absence of the program, the benefit/cost ratio for the category of youth with one good eye was some 3 times larger than that for totally blind youth, for example. The practice of "creaming" and serving the least handicapped youth under the base case analysis assumptions would lead to the largest *economic* return. More realistic assumptions about the inherent earning capacity of each type of handicapped youth, however, calls into question whether emphasizing service to less

Table 9.26

VR BENEFIT/COST RATIO BY TYPE OF HEARING AND VISION
HANDICAPPED YOUTH: SENSITIVITY TO ASSUMPTIONS
ABOUT EARNINGS WITHOUT VR SERVICES

Type and Degree of Sensorial Handicap	Benefit/Cost Ratio with Indicated Percentage Employed at an Average of the Minimum Wage Without VR Services			
	25%	50%	75%	100%
Blind	3.6	2.6	1.5	0.5
Partially sighted--legally blind	4.6	3.2	1.8	0.3
Partially sighted--20/70. up to 20/200 acuity	9.2	6.9	4.6	2.4
One good eye	12.8	9.8	7.2	4.6
Other visual impairment	12.2	9.0	5.8	2.6
Deaf, unable to talk	8.8	5.7	2.6	-0.5
Deaf, able to talk	9.7	6.8	3.8	0.9
Other hearing impairment	10.7	7.5	4.3	1.1
All types combined	9.4	6.9	4.3	1.8

handicapped clients is in fact a rational, to say nothing about equitable, policy from the standpoint of economic return.

Benefit/Cost Analysis: Conservative Assumptions Case

In the preceding section, several of the base case analysis assumptions were varied individually and the conclusion that the program is cost-beneficial in an economic sense did not change. In this section, we shall change three of the most significant base case assumptions and recalculate the benefit/cost ratios for this new set of data and assumptions, which we consider to be more conservative than the base case data and assumptions. If the VR program still appears cost-beneficial even under these rather conservative assumptions that should show the program in the worst reasonable light, we will conclude that the program is effective in a social cost-benefit sense.

In calculating the benefit-cost ratios shown in Table 9.27, we assume the following:

- The discount rate is 8 percent.
- Only 50 percent of the legally blind and deaf youth, and only 70 percent of the less severely handicapped youth, are employed 5 years after closure.
- In the absence of the VR program, 50 percent of both the legally blind and the deaf rehabilitants and 75 percent of the less severely handicapped youth rehabilitants, could have been employed earning the minimum wage on the average.

We emphasize that the true value of the above figures is not known. The values shown are not our best estimates of what those true values are, but rather are conservative estimates made to put the VR program to a hard test. Rather than assume, as in the base case analysis, that without the VR program nearly all of these youth would be unemployed throughout their lives, we assume a majority of them

Table 9.27

VR BENEFIT/COST RATIO BY TYPE OF VISION
AND HEARING HANDICAPPED YOUTH:
CONSERVATIVE ASSUMPTIONS CASE

Type and Degree of Sensorial Handicap	Benefit/Cost Ratio for Total Youth
Blind	1.1
Partially sighted--legally blind	1.4
Partially sighted--20/70 up to 20/200 acuity	2.7
One good eye	4.4
Other visual impairment	3.5
Deaf, unable to talk	2.5
Deaf, able to talk	3.0
Other hearing impairment	2.6

would be employed. And rather than assume a 20 percent unemployment rate for successful rehabilitants after five years, we assume a 30 to 50 percent unemployment rate.

Under these much less favorable assumptions, the program still appears to have economic benefits that exceed its costs to society for all eight categories of hearing and vision handicapped youth. Although these benefit/cost ratios are all greater than one, they are close to one for the legally blind.

Many questions about the proper allocation of resources among handicaps remain unanswered. However, the positive quality-of-life benefits of the program coupled with favorable average economic benefits in relation to cost, imply that expansion of the VR program *could* have very desirable effects. If the program were expanded, however, it should be carefully and periodically reevaluated, because diminishing returns on investment can be anticipated as a larger fraction of the handicapped population is served, and because our calculations have been of average costs and benefits, not the marginal costs and benefits of program expansion, for which data are not available.

Benefits and Costs to the Taxpayers

The previous analysis examined the VR program from the standpoint of society as a whole. The question of just who received the benefits and who paid the costs within society was not considered. In this section we view the VR program from the perspective of an investment decision for the taxpaying segment of society.

The costs borne and benefits captured by the taxpayer are different from those discussed in the previous sections. On the cost side, income maintenance payments during rehabilitation are a real cost to the taxpayer while the opportunity cost of withdrawing the client from the labor force, and other-party payments, are not. On the benefit side, only the increment in taxes paid by the employed handicapped youth, rather than the total increase in income, is counted as a benefit to the taxpayer. An additional benefit is the reduction in future welfare payments that is attributable to the VR program. The costs can be calculated from information presented previously; they are \$29.5 million for VR clients whose cases were closed in FY 1970.

To estimate the increase in taxes paid by rehabilitants, it is necessary to estimate their income distribution. From the RSA-300 forms, the number of persons in weekly income ranges from \$0 to \$20, \$21 to \$40, \$41 to \$60, \$61 to \$100, \$101 to \$150, and over \$150 was calculated for each type of sensorially handicapped youth. It was assumed that each person earned the average salary within his weekly income range except for the over \$150 category, where average earnings were taken to be \$160. The estimated tax was calculated assuming that the young handicapped taxpayer had no other dependents than himself. This may introduce a small upward bias in the benefits that are captured by the general taxpaying population. The estimated federal income taxes paid by rehabilitants in 1970 and the discounted (4 percent) federal tax payments over the lives of the rehabilitants are estimated to be \$4.7 million and \$57.1 million, respectively, assuming the total federal tax payments will be the same each year for the whole group of rehabilitants.

We are now faced with the problem of estimating the taxes paid in the absence of the VR program. If earnings at acceptance are used as the tax base, the taxes paid would be negligible. If different assumptions about the percentage that could earn the minimum wage were made, the net increase in taxes paid by the rehabilitants would be substantially different, as shown in Table 9.28.

Table 9.28

NET INCREASE IN FEDERAL TAXES PAID
BY REHABILITANTS
(In \$ million)

Assumed Percentage Employed Earning Minimum Wage in Absence of VR Program	Net Increase in Federal Taxes
0%	\$57.1
25	46.3
50	35.5
75	24.8
100	14.0

These estimates of tax benefits are lower than Conley's. The major reason for the difference is that Conley assumes that federal tax payments account for only half of the tax liability of the handicapped person. It is difficult to estimate the incidence of the sales tax and property tax on the poor and handicapped. If the client were truly impoverished, he would probably qualify for public assistance and might receive an income comparable to what many of the successful rehabilitants earn. Thus the property tax and sales tax payments could be approximately the same with or without the VR program for some, but not all, youth. By not counting sales and property tax benefits, we will be underestimating total tax benefits. However, the state income tax should be added into the benefits. Revenue from state income tax was 10 percent of federal revenues from the personal income tax.³²

³² *Statistical Abstract of the United States: 1971*, U.S. Department of Commerce, Washington, D.C.: federal, p. 385; state and local, p. 398.

By placing clients in jobs, the VR program reduces the number of handicapped youth who need to rely on public welfare and thus benefits the general taxpayer population. The problems in estimating this reduction are as difficult as estimating increases in earnings. Conley uses welfare payments at acceptance and at closure as a measure of the difference in the amount of welfare payments over the life of the client. This methodology is not directly applicable to youth because many of the handicapped youth are supported by their parents at referral but would have needed welfare later. Therefore, before-and-after welfare payments may not accurately reflect what the client would cost the taxpayer. In the absence of better data, our approach here is to take the average reduction in welfare payments per rehabilitant of any age and assume it is applicable to the youth population under study.

In 1970 there were 266,975 rehabilitants. At referral only 28,308 were receiving public assistance. At closure, this number was reduced to 16,589. The average monthly amount of public assistance dropped from \$3.53 million to \$1.87 million, or a net reduction of \$1.66 million. This works out to a reduction of about \$70 per rehabilitant per year in the aggregate amount of welfare payments. Discounting this reduction over the life of the rehabilitants, the lifetime benefit for hearing and vision handicapped youth would be \$8.4 million.

The benefit/cost ratios for the general taxpayer population are shown in Table 9.29 for several different assumptions about what the client could earn in the absence of the VR program. The welfare reduction benefit has been decreased in proportion to the increase in the percentage employed.

Note that from the viewpoint of the general taxpaying population, the VR program for hearing and vision handicapped youth has benefits that exceed its costs if we assume that 75 percent or less of these rehabilitants are employed at the minimum wage, on the average, in the absence of the VR program. Because we have excluded all sales and property tax benefits, and thus the benefits were underestimated, the program appears cost-beneficial as a taxpayer "investment," just as it was shown to be cost-beneficial from the viewpoint of society as a whole and is cost-beneficial from the viewpoint of the individual VR client.

Table 9.29

BENEFIT/COST RATIO FOR TAXPAYERS

	Assumed Percent Employed Earning the Minimum Wage in Absence of VR Program				
	0%	25%	50%	75%	100%
Benefit/cost ratio	2.4	1.9	1.5	1.0	0.5

NEEDED IMPROVEMENTS IN VOCATIONAL SERVICE PROGRAMS

Improvements needed in the delivery of vocational services to hearing and vision handicapped youth are discussed here; our recommendations appear in italics. Potential federal roles in bringing about these improvements are presented in Chapter 2.

Expand the Vocational Rehabilitation program to serve a larger fraction of the hearing and vision handicapped youth population. This program not only improves the quality of life of youth served by increasing their ability to function more independently, to obtain employment, and to work at higher quality employment, but it also appears to yield economic benefits (reduced service cost later in life, reduced welfare, increased taxes paid, and increased earnings) that exceed the costs of the program. Even with assumptions designed to subject the program to a difficult test, the economic benefits exceed costs to a society as a whole and to the taxpaying population for every one of the eight categories of type and severity of hearing and vision handicap that we considered. Insufficiency of funds was the problem most often cited by VR agency administrators we surveyed in the 50 states.³³ A recent General Accounting Office report on the VR program indicated that "the number of persons needing vocational rehabilitation services has far exceeded the number of persons that have been served under the program" and that "the number of persons rehabilitated annually, although increasing, is still not as great as RSA's estimates of the number becoming eligible each year."³⁴ The need for additional facilities is also large.³⁵

Establish clear guidelines on the categories of handicapped persons to be given priority in the receipt of Vocational Rehabilitation services, and restructure existing incentives so that those categories are given priority, including abolition of the simplistic use and reporting of successful case closures. One might assign highest value to serving those with the severest handicaps (as the Rehabilitation Act of 1973 does) or to young persons, unemployed persons, persons who show promise of yielding high economic benefits in relation to cost, etc. One might take a dynamic and flexible approach depending on the level of vocational impairment. For example, "normal" youth might receive no special vocational services unless they are unemployed after leaving school, in which case the State Employment Service could give them job information. All handicapped youth might be screened before leaving school, and mildly sensorially handicapped youth might automatically be given both job information and placement assistance upon leaving school, and then if they are not vocationally successful, full VR services could be given. And severely sensorially handicapped youth could be automatically offered VR services beginning well before their scheduled departure from school. Whatever the priorities assigned, the program will come closer to meeting its goals with its available resources if effort is concentrated on finding, accepting, and serving clients in priority categories. Even before passage of the new Act, we seriously question whether the VR program legislators and administrators really intended that 69 percent of the young visually impaired clients should be drawn from the categories "one good eye" and "other visual impairment" rather than from the more severely handicapped "partially sighted" and "blind" categories. For visual types of impairment, the charge that some VR counselors inflate their success statistics by "creaming" and selecting easy-to-serve clients appears to be true. To best satisfy the intent of the Rehabilitation Act of 1973—that the most severely handicapped persons be served first—much better definitions and reporting, including disaggregation within each type of handicap by degree of severity, are needed.

At present, one major way in which the system judges and reportedly rewards its personnel is based on total successful closures and the percentage of successful

³³ See R-1220-HEW, p. 82.

³⁴ *Effectiveness of Vocational Rehabilitation in Helping the Handicapped*, Report to Congress by the Comptroller General of the United States, Number B-164031 (3), April 3, 1973.

³⁵ R-1220-HEW, p. 85.

closures in relation to clients served. The use of gross numbers of successful closures provides disincentives to serving hard-to-rehabilitate clients, disincentives to an individual VR counselor's conserving on program costs, disincentives to offering a wide choice of occupations to clients, and disincentives to train for more than minimal pay and skill occupations. The much discussed, but as yet unimplemented, concept of disaggregating the clients served by degree of difficulty of rehabilitation and type or quality of "gainful employment" obtained is a good one. Either a set of measures of "effect" of each counselor and VR agency, or a weighted measure giving higher value to higher priority types of results, would be a major improvement over the present simplistic measure with its inherent disincentives to desired performance.³⁶

Conduct thorough evaluations of state programs that have significantly better than average gainful employment, occupational, and earnings results for handicapped youth, to determine desirable characteristics of those programs that may be exportable to other states. The reasons for low average earnings of successful VR clients, despite extensive and costly services, and the often-heard complaint about the narrow range of occupational choices offered clients, should be investigated more vigorously than they are now so that this dual problem at least can be alleviated. The current programs in the 50 states are natural "experiments" in alternative methods of serving these youth; they represent a wealth of relatively untapped data that should shed light on program effectiveness as a function of the type and quantity of services provided, expenditures, means of providing the service, type of handicapped youth, and so forth. The current system of reporting on individual clients is the most comprehensive of any we observed in federal programs, but it still has some deficiencies. For example, some of its categories of reasons for rejection or failure to rehabilitate a client are not very illuminating, and it does not adequately mine the wealth of its own data as a means of discovering and evaluating problems and options for program improvement.

Increase the number and improve the geographic distribution of specialists in vocational services to hearing and vision handicapped persons. Special expertise is needed in serving both of these categories of handicapped persons; the need is especially critical for profoundly deaf clients with little or no oral communication skill.³⁷ Most states now have such specialists, but care should be taken that they are available at least in every major metropolitan region. This holds for both the Vocational Rehabilitation program and the State Employment Service program.

Increase the coordination between Vocational Education, Vocational Rehabilitation, and State Employment Service programs, and establish a mechanism for outreach to all hearing and vision handicapped youth in their latter school years, with follow-up after the time of leaving school. In our interviews with various of these agencies in five states, coordination varied from excellent to practically nonexistent. By and large, however, it appeared that these three programs operate fairly independently of one another at the client level, although they have very closely related purposes and often have "coordinating committees" at the agency manage-

³⁶ For a discussion of these issues, see Ronald W. Conley, "Weighted Case Closures: Concepts, Problems," *Rehabilitation Record*, September-October 1973; J. H. Noble, "A Simple System for Weighting Case Closures," Rehabilitation Services Administration, Office of Planning and Policy Development, Washington, D.C., 1973; K. W. Reagles, G. N. Wright, and A. J. Butler, "Toward a New Criterion of Vocational Rehabilitation Success," *Rehabilitation Counseling Bulletin*, June 1972; and A. Hawryluk, "Rehabilitation Gain: A Better Indicator Needed," *Journal of Rehabilitation*, September-October 1972.

³⁷ S. P. Quigley (ed.), *The Vocational Rehabilitation of Deaf People*, U.S. Department of Health, Education and Welfare, Publication (SRS) 72-25037, Washington, D.C., 1972; and N. Tully, "Trends in the Professional Preparation of Rehabilitation Workers with the Deaf," *Deafness Annual*, Vol. 3, Professional Rehabilitation Workers with the Adult Deaf, Inc., Silver Spring, Maryland, 1973.

ment level.³⁸ They also tend to serve clients that come to them, rather than setting out well-defined priority categories of youth who need service and then reaching out to find those youth. It would be inexpensive to arrange for automatic referral to or outreach by VR, for example, for all hearing and vision handicapped youth, both in school and applying for State Employment Service assistance. Such a stratagem would provide VR with fairly comprehensive rolls of potential clients from which they could select high-priority types of youth. The precedent is the referral program for disabled welfare clients.

One possible follow-up mechanism not now used is to monitor former clients' earnings through Social Security records.

Modify the State Employment Service program to provide more trained specialists in the placement of hearing and vision handicapped persons, and give those specialists a caseload well below that of current SES personnel. The current workload of SES personnel is so heavy that it appears very difficult for them to provide meaningful job information to handicapped persons, let alone placement service. In addition, the current information systems used in the states are improving but still leave much to be desired in matching handicapped clients with available jobs.

³⁸ The Vocational Education Act Amendments of 1968 require cooperative arrangements between Vocational Rehabilitation and Vocational Education agencies, and the Rehabilitation Act of 1973 (P.L. 93-112) requires that state VR annual plans provide for intergovernmental cooperative arrangements.

Chapter 10

INCOME MAINTENANCE

INTRODUCTION

This chapter discusses programs that provide direct financial aid to a handicapped youth or his family, principally in the form of cash transfers rather than in-kind aid such as in the Food Stamp program. The chapter briefly summarizes current financial assistance programs, describes the nature of expenditures for various types of services needed by handicapped youth, and presents recommendations for improvement. Earlier chapters have discussed human resources development programs that contribute to economic security, such as education and vocational rehabilitation, and programs that provide services to the family instead of cash transfers.

CURRENT INCOME MAINTENANCE PROGRAMS ¹

In 1970, welfare agencies spent some \$635 million to aid about one million physically and mentally handicapped youth. Of this amount, about \$18 million and \$25 million, respectively, went for assistance to vision and hearing handicapped youth. The federal, state, and local shares were 54.6, 34.6, and 10.8 percent.

The four primary programs serving physically and mentally handicapped youth are Social Security Disability Insurance (SSDI); Supplemental Security Income (SSI) providing aid to the aged, blind, and disabled;² Aid to Families with Dependent Children (AFDC); and Income Tax Exemption for the Blind (ITEB). The estimated numbers of physically and mentally handicapped youth served by these programs in 1970 are: SSDI, 14,700; AB, 4000; APTD, 29,000; AFDC, 976,000; and ITEB, 9000. The average yearly expenditure per youth served is about \$635.

Prior to the Social Security Amendments of 1972, most youth given aid were eligible *not* because of their handicaps, but because they were part of a family receiving Aid to Families with Dependent Children, and the AFDC program does not make allowance for the added expense of the handicapped child. The 1972 amendments permit youth from needy families to draw significantly increased aid based on the existence of a handicap, under the new combined Supplemental Security Income program providing aid to the aged, blind, and disabled. The SSI does not have the age restrictions of the former Aid to the Blind (which in most states did not serve persons less than 16 or 18 years old) and Aid to the Permanently and Totally Disabled programs (which did not serve anyone less than 18 years old).

The federal government uses two primary functional mechanisms in this program area: direct provision of assistance in the SSDI and SSI programs, and funding of assistance through state and local agencies in the large AFDC program. Federal involvement in financial assistance has grown to the point where the majority of the

¹ For a more detailed description of these programs, as they relate to handicapped youth, see Chapter 7 of Rand Report R-1220-HEW.

² SSI replaces two programs that provided financial aid to handicapped youth: Aid to the Blind (AB) and Aid to the Permanently and Totally Disabled (APTD).

funds expended on needy handicapped youth are federal, and three of the five major programs are federally operated. This dominant federal role apparently evolved for two main reasons: (1) state, local, and private sources have had insufficient financial resources to provide socially desirable minimum income levels to an acceptable fraction of the needy population; and (2) under state and locally operated programs, there has been a socially undesirable inequity in the distribution of funds across states. While authorities disagree on what level of financial aid is adequate, and what distribution of funds is equitable, the President's Commission on Income Maintenance Programs concluded that existing aid levels were inadequate and that the distribution of aid was inequitable.³ In brief, the federal government acquired its present role because it had both the funds and the inclination to distribute them to the needy population across states more equitably and to raise the payments to a more nearly adequate level. Although their roles have gradually diminished, both state and local governments are still very much involved; they supply nearly half the funds expended for needy handicapped youth, and operate the AFDC program.

The Federal Social Security Insurance Program is based on a social insurance model wherein an employee and his employer, and self-employed persons, contribute to the system to provide coverage against disruption or reduction of the worker's income due to disability, death, or retirement. Payment levels are not based primarily on need, but on the rate and number of quarter-years of previous contribution to the system, subject to maximums and minimums. Under the Childhood Disability provisions of this program, a person aged 18 or older who has been disabled prior to his twenty-second birthday, and who is the child or grandchild of a retired or disabled worker, could receive payments of up to \$166 a month beginning September 1972, while the disabled child or grandchild of a deceased worker could receive up to \$256.90 beginning September 1972 if he earns \$125 or less per month. Because most handicapped youth under 22 have neither accumulated the required previous earnings record, nor have a retired, disabled, or deceased parent, only a small fraction actually receive benefits, averaging about \$62 a month, from this program. The breakdown by type of handicap is approximately 1 percent visual and 2 percent hearing impaired.

Prior to 1972, the AB and APTD public assistance programs were operated within the states and jointly funded by federal and state governments. The Social Security Act of 1972 combined these two programs with Old Age Assistance (OAA); the new combined program will be federally-funded and operated, effective in 1974. The new program, called Supplemental Security Income (SSI), established uniform basic payment levels for recipients in all 50 states and the District of Columbia. (Individual states may supplement these federal payments, which could take into account the variations from state to state in the cost of living.) Eligibility requirements, which previously varied from state to state, are also uniform for new applicants. Persons of any age can be eligible, and those 65 years or older need not be blind or disabled. Thus, the new SSI program alleviates many past inequities in payment levels and eligibility requirements which varied from state to state.

Under a state plan in effect as of October 1972, people on the APTD rolls for December 1973 and for at least one month prior to July of 1973 were considered disabled for purposes of the new program, and were considered to meet the resource requirements of the new program. These same provisions apply to people on AB, except that they need not have been on the rolls for at least one month prior to July 1973. These persons were transferred to the SSI rolls on January 1, 1974 if they also

³ *The President's Commission on Income Maintenance Programs, Background Papers*, U.S. Government Printing Office, Washington, D.C., November 1969.

met the other requirements of Title XVI, such as income, age, relationship, and the like. A "blind" applicant, however, who is engaged in employment may exclude his working expenses from his earned income. New applicants must meet all requirements of the new program. For a disabled applicant to qualify for payments under the new program, based upon a disability other than visual, he must meet the income and resources test and be unable to engage in any substantial gainful activity by reason of a medically determinable physical or mental impairment that either can be expected to result in death, or has lasted (or can be expected to last) for a continuous period of not less than 12 months. A child's income and resources include those of his parents or his parent's spouse, if his parent or parent's spouse lives with him, whether or not they are available to him, except to the extent "determined to be inequitable." "Blind" applicants must meet the income and resources test and must have central visual acuity of 20/200 or less in the better eye with the use of a correcting lens, or restriction of visual field to 20° or less. Ability to engage in a substantial gainful activity is not a factor in determining eligibility for the blind. One question to be asked is why, if blind, one must be blind and needy to qualify, whereas, if disabled, one must be disabled, needy, *and* unable to work.

As amended by P.L. 93-233, payments for an eligible person who does not have an eligible spouse were set at the rate of \$140 per month beginning in January 1974, reduced by the amount of the individual's countable income. Payments for an eligible person who has an eligible spouse will be at the rate of \$210 per month in January 1974, reduced by the amount of the person's countable income (combined with that of his or her spouse). P.L. 93-233 will also raise these figures to \$146 and \$219, respectively, effective July 1974. These payment levels are higher than the old program payment levels in most states, and any state may supplement the federal payment level if it wishes to. However, the level of payment above the federal minimum to people on the state rolls in December 1973 must be maintained in order to get matching federal funds for Medicaid.

Under the pre-1972 AB program, the average monthly grant ranged from \$59 in one state to \$177 in another, with a United States average of \$104. Coupled with varying payment levels were varying AB eligibility standards by age (5 years in one state, 18 years in many others), by whether or not property liens were required, and by the allowable value of home and personal possessions. Five percent of all AB clients were under 22. We estimated that in 1970, there were 4076 recipients under 22, upon whom a total of \$5,550,000 was expended. The annualized expenditures per recipient varied across the states from \$714 to \$2058 and averaged \$1372. The number of recipients per 100,000 state population aged 0 to 21 varied from 0.5 to 19. The fraction of total program expenses devoted to administration, service, and training rather than financial assistance varied across states from 5 to 32 percent.

The APTD program had a U.S. average monthly recipient grant of \$97 in 1970. Total annual expenditures per recipient averaged \$1229, but varied across states from \$724 to \$1837. A total of 29,000 physically and mentally handicapped persons aged 22 or less that year received APTD, or 3.4 percent of all APTD recipients. Age requirements were uniform across states at 18 years, but other eligibility requirements varied markedly. The number of recipients aged 18 to 21 per 100,000 state population averaged 205, but ranged from 27 to 625. Perhaps the most graphic example of the inequity of the payments distribution is the fact that nearly half of all APTD payments to recipients under 22 in 1970 were paid in California.

In an effort to better understand the variations across states in AB and APTD assistance to handicapped persons, we investigated the relationships between factors such as federal funding to the state for these programs, state expenditures for these programs, the number of aid recipients and the number of handicapped per-

sons in the state, total state revenues, and personal income levels. (Appendix B summarizes our efforts and presents a review of other previous studies in this area.) We had limited success in "explaining" the variation across states, and conclude that the determinants of state and federal expenditures for financial assistance to handicapped persons are probably too complex to be understood using currently available data and econometric models with simultaneous equations.

The AFDC program provides financial assistance to needy families with children, but to handicapped children only if they belong to families receiving AFDC. In March 1971, the average monthly payment was only \$49.60 per recipient person. However, the program is so large that an estimated \$580,868,000 was expended on 975,920 handicapped youth in 1970. This is by far the most massive financial assistance program serving handicapped youth, and an excellent contact point for identifying those who need nonfinancial types of assistance. As we indicated in Chapter 4, progress in AFDC in implementing a mandated screening program has been slow.

The legally blind are the only handicapped persons allowed to claim an additional exemption from federal income taxes. The exemption may be claimed for a taxpayer or for his spouse but not for other dependents; parents cannot claim an extra exemption for handicapped children. At a marginal tax rate of 20 percent,⁴ the \$750 exemption means a tax reduction of \$150 per person. This is, in effect, a financial assistance payment to the legally blind person.

In our survey of state welfare agencies, problems cited in the present system included lack of financial support for the programs and inadequate coordination of services.

FINANCIAL AID AND THE NATURE OF EXPENDITURES FOR HANDICAPPED YOUTH

In considering an income maintenance program for handicapped persons, and in considering the issue of whether to provide funds directly to the families or indirectly through payments to service providers, one must examine the nature of the services and expenditures needed by the handicapped person. Several types of service expenditures are discussed below.

Prevention. By definition, expenditures for prevention cannot be part of an income maintenance program for handicapped persons. Payments could be provided for preventive medical care in health programs (e.g., as a vaccination program or as a mandatorily covered expense under health insurance), and some small portion of public assistance payments to families about to have a child or that have children who are not physically or mentally handicapped, can be considered as prevention expenditures because of the known linkage between nutrition, for example, and handicapping conditions.

Identification. Also by definition, identification cannot be funded as income maintenance for handicapped persons, but is a necessary predecessor of that income maintenance.

Direction. Direction is an information-based service that depends on a steady flow of funds to enable the regular collection and updating of information, coordination with other service agencies in providing an appropriate mix of services to a child, and adequate follow-up for the children. Since, in general, this service is not

⁴ The 1972 marginal tax rate for a married person filing jointly with a taxable income of \$4000 to \$8000 was 19 percent, while the comparable rate for a single person earning \$4000 to \$6000 was 21 percent.

provided well now, since no agency such as the Regional Direction Centers we propose in Chapter 3 exists in most areas, and since current direction expenditures are a hidden implicit portion of expenditures for other services such as medical care, education, welfare, and rehabilitation, it does not appear practical to provide funds directly to families for purchase of direction services.

Counseling. The need for counseling is highly variable, and counseling is often provided as part of a package of services from a service agency. If funds are provided directly to a family for purchase of counseling, the amount should be determined on an individual need basis and reassessed periodically.

Medical Treatment. With the extremely high variance over time of medical expenditures for a handicapped child, it is highly impractical to expect a family to pay all their medical bills from a fixed level of income maintenance. Some sort of health care program appears essential, although the forms it might take cover a wide range, including the present Crippled Children's Service program and the proposed National Health Insurance. A family in financial need could be given the insurance or other health care program service or, through regulations on the receipt of income maintenance, the family might be required to purchase health insurance of an approved type and be expected to pay for a small portion of the general medical expenses. If an insurance mechanism is adopted, however, we recommend not applying such a "deductible" to insurance payments for services directly related to the handicap, such as screening and diagnostics, medical or surgical treatment of the handicapping condition, and provision of sensory aids. Applying a "deductible" to those types of services could result in the child's being denied essential services, while yielding relatively little monetary savings.

Education. Current practice is to provide funds for special education to the education agency directly rather than to the families. One practice in very limited use is to give the family a special education "voucher," whereby special education services unavailable locally can be obtained from a school in another region or another state.

Vocational and Special Training, and Job Placement. The need for these services is also highly variable among handicapped youth and over time. Consequently, if funds are provided directly to families for purchase of these services, the amount should be determined on an individual need basis.

Sensory Aids. While the need for one or more sensory aids by hearing and vision handicapped youth is nearly universal, the original costs and time intervals between replacement of personal aids is not constant. Consequently, here again, if funds are to be provided directly to the family for purchase of the aids, the amount of those funds should depend upon the individual degree of handicap and expected life of the aid.

Transportation. For handicapped youth and, in certain cases, for the escorting family member, special transportation needs will arise primarily in conjunction with obtaining some other service such as special education, medical treatment, or some types of special training. Since the added costs of transportation depend on how often those other services are needed and how far it is from the child's residence to service facilities, transportation costs are not uniform and are better handled for financially needy families as part of the costs for those other services—that is, as a segment of the special education budget and as a covered expense under a health care funding program, rather than as a fixed income supplement.

These expenses could also be included as a variable component of an income maintenance program, with the payment determined separately for each individual and with required certification of receipt of other services to which the child must travel.

Necessities of Daily Living. Historically, income maintenance of a fixed amount each month has been provided to help financially needy families to purchase housing, clothing, food, and other goods and services needed by both handicapped and nonhandicapped persons in daily living. The amount a family needs for these types of expenditures for their handicapped child may be slightly higher than that needed for a "normal" child. However, reliable data on the degree of additional need are not available.

NEEDED IMPROVEMENT IN INCOME MAINTENANCE PROGRAMS

Improvements needed in the provision of financial assistance to hearing and vision handicapped youth are discussed in this section; our recommendations appear in italics.⁵

Undertake research and evaluation to obtain much better planning information on the financial needs of handicapped persons. Data on what these programs are accomplishing with respect to handicapped persons are woefully inadequate. Decisions on levels of financial assistance to the handicapped person and his family must be based upon very little information in two essential areas: what the extra financial needs of various groups of handicapped persons are, and what different levels of support to the handicapped person mean in terms of the total quantity and quality of goods and services that can be purchased with the assistance.⁶ The lack of data is a severe impediment to making informed decisions on "need" and "adequate" levels of income assistance. Although many authorities believe the present payment levels are inadequate, they have neither agreed upon definitions of adequacy and payment levels necessary to provide a socially acceptable standard of living, nor studied them in the depth warranted by the importance of the topic. Further, the newly implemented SSI program, with its new regulations, needs careful evaluation to see if it is functioning as intended, and how well it is functioning.

Limit direct cash transfers to handicapped youth and their families, in lieu of other mechanisms of making service available, to coverage of normal daily living expenses and to relatively minor special service expenses. This chapter earlier covered the point that, with the major exception of expenditures for daily living, such as for food, housing, and clothing, each of the other major services involves either: (1) expenditures before the child is handicapped or known to be handicapped, in which

⁵ For a review of welfare reform efforts over the last decade, see Gilbert Y. Steiner, *The State of Welfare*. The Brookings Institution, Washington, D.C., 1971. An earlier comprehensive study of welfare in general is J. N. Morgan et al., *Income and Welfare in the United States*, McGraw-Hill, New York, 1962. Current issues in welfare are discussed in a series of papers published by the Subcommittee on Fiscal Policy of the Joint Economic Committee of the Congress of the United States, entitled "Studies in Public Welfare," Papers 1 to 12, dated April 10, 1972 through December 3, 1973. Another Rand report provides an extensive bibliography on welfare-related issues; see D. M. de Ferranti, *Basic Research on Welfare Policies: The Welfare and Non-Welfare Poor in New York City*, The Rand Corporation, R-1381-RC, (forthcoming). Finally, several recent Rand Corporation reports have examined fundamental issues concerning assessment of the effects of various income maintenance programs, these reports go into far more detail than is possible in an overview study like ours. See, for example, J. I. DaVanzo, *An Analytical Framework for Studying the Potential Effects of an Income Maintenance Program on U.S. Interregional Migration*, R-1081-EDA, December 1972; and Dennis N. De Tray, *A Conceptual Basis for the Study of Welfare Reform Effects*, R-1066-DOC, September 1972.

⁶ While this is a major problem for many groups, it was cited as especially critical for handicapped persons by the Commissioner and several other high-level personnel in HEW's Assistance Payments Administration, in our interviews with them in March 1972.

case the family, by definition, cannot be given dollars in lieu of services; or (2) highly variable and often unpredictable levels of expenses that are not uniform over time and that depend upon the specific needs of the individual handicapped child. In the latter case, the financially needy family could be given an income supplement to cover the cost of the special services. It is desirable, however, to avoid expenditures on families who do not need special services in a given time period, to avoid the possibility that the family will not save the extra funds for the child's future needs, and to avoid the possibility that service needs will exceed the amount of money the family could save from an income supplement. We therefore believe that if funds are to be given to a family for purchase of major goods and services other than those that nonhandicapped persons need for daily living, then it is essential to base the amount of those funds on the handicapped child's periodically assessed need for services. Further, since the child is the one who needs the special service, but is not necessarily the one who decides how the family will spend the money, we believe it highly desirable to protect both the child's rights and society's investment by requiring that any major special income supplements, above income maintenance levels for daily living, be expendable only for meeting the child's specific needs.

If these are to be the procedures, however, there appears to be no persuasive reason for funneling the money through the family rather than directly to the service providers; giving the money to the family does little more than add yet another link to the chain of money-handlers.

Either revise the income tax "extra personal exemption" program to include all severely handicapped persons with relatively low incomes, not just legally blind persons who file a tax return, or restructure the entire program concept. The present extra personal exemption program for legally blind persons is clearly discriminatory; if the program is justifiable for them, by the same rationale it is justifiable for other severely handicapped persons. This program can be questioned on the grounds that it provides a "little something extra" for one type of handicap but not for other types with apparently similar needs, for tax-return filers but not for their children, for persons with sufficient income to pay income taxes but not for others with lesser incomes, and equally for both high-income persons and more needy lower-income persons. This program needs to be thoroughly studied and then revised.

One possible option would be to grant an extra one or two personal exemptions to each taxpayer and dependent who is severely handicapped. Another would be to permit deductions of a portion of all necessary extra expenses incurred because of the handicap of the taxpayer and any of his dependents, with the portion dependent upon the taxpayer's income level and with a maximum ceiling on the amount of the deduction; this is implicitly a voluntary identification program, with the incentive being reduced taxes. A third option would be a revised type of income tax program for handicapped persons that provides benefits ranging from nothing for relatively high-income taxpayers to expense deduction for lower-income taxpayers, to an income "supplement" rather than an income "tax" for handicapped persons in the lower income range; clearly, an income supplement for the handicapped is one major and very flexible alternative to the present Supplementary Security Income program of income maintenance for handicapped persons. Annual qualification might be required and would be voluntary, but could be conditioned on a test of employability or on the person's having participated in other programs such as vocational rehabilitation.

Government contact with youth in families receiving income maintenance represents an opportunity for identification of handicapping conditions, for transfer of youth from the AFDC program to the higher payment SSI program, for diagnosis and

treatment under Medicaid or some other health program, and for direction to programs that can supply other needed services. This opportunity should be fully exploited. As we indicated in Chapters 3 and 4 of this report and in Chapter 5 of R-1220-HEW, this opportunity is not being fully exploited, despite special provisions in the Medicaid program for identification and treatment of handicapped youth, and special provision for referral of disabled financial assistance recipients to the Vocational Rehabilitation Program.

Part III
**EXPERIENCES AND RECOMMENDATIONS OF THE
HANDICAPPED POPULATION**

Chapter 11

SURVEY OF THE HANDICAPPED POPULATION

OVERVIEW FROM THE HANDICAPPED POPULATION'S VIEWPOINT

Evaluation of current and future service policies for handicapped youth requires information from both service providers and recipients. The sample of 77 families personally interviewed had received aid from 665 different service providers, and was selected about equally from (1) the three diverse states of California, Massachusetts, and Wyoming; (2) four types of handicapped youth: the totally blind, partially sighted, profoundly deaf, and hard of hearing; and (3) four age groups, 0 to 5, 6 to 12, 13 to 17, and 18 to 21. Although the sample is too small to use for other than heuristic purposes, the results provided useful insights into the needs and experiences of the handicapped, benefits of various services, and problems of the service system. The family survey should therefore be regarded as a supplement and cross-check on other analyses performed in this project.

When asked to determine the relative importance of various service needs, families overwhelmingly rated education highest. Medical services and sensory aids were also very important. Services considered and rated less important were vocational training, financial aid, transportation, job placement, counseling, and recreation. (We discussed the importance of identification and direction services, but did not ask the families to rate them.)

When asked if the 665 services had benefited their children, 62 percent of the respondents said they were very beneficial, 24 percent said they were somewhat beneficial, and 14 percent felt the services had yielded little or no benefit.

From the thoughtful and often well-informed opinions of the surveyed parents, a picture emerges of a service system that often surpasses the expectations of its users but has some important shortcomings.

Our interviews led us to make the following major observations:

- In general, service recipients appreciate the service system but are not fully satisfied with it;
- Initial identification of the handicapping condition is a major problem;
- Information about available services and direction to the appropriate mix of services is severely lacking;
- The range of services available within a reasonable distance of the families' homes is often very incomplete; and
- The quantity of service available is insufficient to meet the need.

Lack of Full Satisfaction with the Service System

Families were generally grateful for the available services, but they saw room for significant improvement.

When asked to assess their experiences with all services and rate their satisfaction with the service system as a whole, 40 percent of the families said they were very satisfied, about half said they were satisfied but not completely, and only 5 percent said they were definitely not satisfied. Parents of younger children and of less severely handicapped children were least likely to be satisfied. When asked

individually about each of the 665 services used, dissatisfaction was reported for 13 percent.

The Problem of Identification

The full set of needed services obviously cannot be given to a handicapped child until the handicap has been identified, and at present identification is too often haphazard, catch-as-catch-can. The parents in our sample reported that initial identification of the impairment was too frequently inaccurate (actual errors were reported by over 10 percent of the families interviewed) or was not made early enough to enable preparations for arranging as nearly normal development as possible for their children. Cases in point were profoundly deaf children who needed service during the preschool language development years. Several sets of parents of these children suspected a problem and consulted doctors. One child's pediatrician refused to believe the mother and would not test; four other children's doctors remarked variously that "nothing was seriously wrong," the child would "grow out of" the problem, it was "just a bad cold," or the child was "just fine." Another child was incorrectly labelled autistic, and another was treated by a psychologist for emotional disturbance for two years before his profound deafness was discovered.

The same problems occur with visual handicaps. One nearly blind child reached the first grade before her eyes were tested. Recounting the incident, the mother told us, "The kindergarten teacher just thought she was dumb." Still another partially sighted child was incorrectly called retarded.

Lack of Direction

The most frequently mentioned of all problems was the lack of *direction* — information about the mix of services needed and where to obtain them. Two-thirds of the families had difficulty finding appropriate services. Direction is presently a major problem because in most areas *no one* has all the information needed or the responsibility to coordinate help for families. The result is that there are gaps or delays in the services received, or inappropriate services are delivered.

Less than half the families were fully pleased with the appropriateness of the amount and variety of services received. Initially contacting the service system was typically either a matter of fortunate chance or time-consuming, frustrating search by the parent; once initial contact is made, the search for service is a chain-like process of going from one agency to another, one at a time, rather than a process of sitting down and choosing among an array of alternatives. The parents' feelings about direction were nicely summarized by one of them: "*Someone* should do it!"

Gaps in Available Services

Fully 60 percent of the families reported that needed services were not available within a reasonable distance. For example, local schools may offer services designed for blind youth but none for the more numerous partially sighted; several children had to go to residential schools so far away that their parents found it difficult even to visit them; eight families moved to obtain appropriate educational services; several families could not obtain speech therapy anywhere near their homes; mobility training was seldom available for young children; and vocational training options were said to be very limited.

Insufficient Supply of Service

Even when a service is provided, the supply may be limited. Some parents had trouble getting their children into nearby school programs because the classes were full. And in one state where high-quality counseling and direction is available, the agency is said to be so understaffed it is unable to see each family more than once or twice a year. In total, only 40 percent were fully pleased with the overall *amount* of services received.

Sensitivity of Service Personnel

Most families were pleased with the service personnel, but a small minority (approximately 10 percent) related experiences indicating insensitivity to the feelings or needs of the handicapped child and his family. Perhaps the worst case was the teacher who punished an 8-year-old girl for "disruptive behavior" by placing a paper bag over her head; being deaf, this represented loss of the child's major form of contact with the world, and she was terrified. Some parents complained that doctors would not take the time to explain anything or would treat their children as cases rather than as persons, or that the hearing-aid dealer was unable to work well with their young children. For example, one woman, suspecting deafness, had taken her child to a clinic for evaluation. After a long series of tests, they were sent home with instructions to call later in the afternoon for the results. Shortly before 5 p.m., the woman finally reached her doctor; sounding rushed and a bit annoyed at being interrupted, he told her, "Your child is fine, fine—oh, except that he's deaf." Later the mother realized that, after dealing with very severely and multiply handicapped children, the doctor might indeed have thought her son to be relatively lucky. But she, though not easily upset, was near hysteria when her husband came home. Another form of insensitivity is illustrated by the family whose child "wasted nine years" in a school that taught only oral communication for deaf youth, before they were told he was not progressing and should go to a school that used manual communication.

Parental Views of Government Roles

To find out what parents thought of various ways in which the government could help them meet their children's special service needs, we questioned parents about a few alternative possibilities.

Asked whether they preferred private to governmental service sources, about half the respondents said they did not care. As one said, "As long as help is there, I don't care *where* it comes from." Of those expressing a preference, equal proportions said "yes" and "no" (about 23 percent in each group). However, only 5 percent of the sample thought that any service role now being undertaken by any government agency was inappropriate. Most parents could not conceive of an "inappropriate" role.

A government role to provide information about available services was enthusiastically endorsed by over three-quarters of the families surveyed. Several also suggested, without being asked, that the government should supply more information to the public so as to "make it acceptable to have a handicap."

We asked if the parents would like to get financial vouchers with which they could obtain services from private sources of their choice, rather than directly from a government agency. We had a hard time explaining this possible government role to the families, and most were at best lukewarm toward the concept, remarking that they would not know where to spend the voucher or that unscrupulous service

providers would abuse the system and take advantage of them. In other words, they would still need a direction service.

We also asked their views about a national insurance program whose benefits would include payments for the added service needs of handicapped youth. About half the parents liked the idea; 25 percent did not; and the remainder thought maybe they would be interested. Several also noted that families without handicapped children probably would not like to pay for the insurance.

DESCRIPTION OF THE SURVEY

Survey Design

This survey involved personal interviews with a sample of 77 families of youth with impaired vision or hearing. The sample size was dictated by the need to have a reasonable number of youth in each subclassification (state, age, handicap) consistent with budget and time constraints on this research. We selected three states—California, Massachusetts, and Wyoming—from the five in which members of the project had extensively interviewed personnel in various state agencies, because the states had diverse types of service systems about which we were knowledgeable, because the states were different in size, population, region, and extent of urbanization, and because the contacts we had made provided a basis for requesting a wide variety of referrals.

Families were interviewed, rather than the handicapped children themselves, because we felt that youth, especially very young persons, might react unfavorably to being singled out as handicapped, impaired, or “different” in any fashion, or to the implied criticism of those providing service. In the case of youth over age 17, especially those living away from home, interviews were sometimes conducted with the handicapped person rather than the family, but these were the exceptions.

As one source of families, we contacted staff members of agencies with whom the project staff had dealt in the earlier phase of the study. Although this approach excludes respondents who are not being served by some agency, this is not a severe drawback. The survey is designed to tap attitudes and opinions concerning the system of services presently offered, and those currently in contact with the system are more likely to have accurate memory and detailed opinion about it. We also attempted to reach persons not served by the government programs by requesting referrals from private clinics and physicians, as well as from associations of the handicapped and from an assortment of *types* of agencies serving the handicapped. We also requested referrals from certain schools (both those serving the handicapped exclusively and regular schools with programs for the vision or hearing impaired), welfare agencies, and rehabilitation programs. This provided a wider range of responses and helped prevent the distorted patterns that would occur if agencies referred us only to their “star clients.” We explicitly requested names of parents whose children were representative of the handicapped youth served, and requested *three* names for each interview to be conducted, thus making it more difficult for the agencies to select their “stars.”

Other strategies designed to ensure a fairly wide range of responses to the survey include a threefold breakdown of the sample—by age, handicap, and geographic location. Four age groups are separated (0 to 5 years old, 6 to 12, 13 to 17, and 18 to 21). The divisions correspond roughly to life stages: preschool, elementary school, intermediate school, and young adulthood.

The sample is also broken down by handicap: blind and partially sighted for the visually handicapped; deaf and hard of hearing for the auditorially handicapped.

In seeking referrals, we tried to obtain equal numbers of families in each of the four age groups, four handicap categories, and the three states. When the interviews were completed, we found that 19 percent of the youth were under 6 years of age, 31 percent were 6 to 12, 25 percent were 13 to 17, and 25 percent were 18 to 21. Of the 77 families surveyed, 22 percent included a blind child, 26 percent a partially sighted one, 27 percent a deaf child, and 25 percent a hard of hearing child. We conducted 26 interviews in California, 25 in Massachusetts, and 26 in Wyoming.

We developed the questionnaire (see Appendix A) after examining, as models, several other instruments for assessing the service needs of handicapped persons and the effects of programs serving them. Using many open-ended questions, it attempts to elicit the past, present, and projected future needs of the respondents as well as their experiences with and evaluations of specific agencies' services. One section of the interview asks how the client sees the service system as a whole—what unmet needs he perceives, what difficulties he has had in getting information or assistance. Attitudes toward alternative roles for government as a purveyor of services are also explored. The questionnaire attempts to get the "target population's viewpoint" in a number of topical areas, for example:

- Needs for services;
- Deficiencies in single services or in the mix of services offered;
- Problems with the agency, mechanism, or personnel providing services;
- Goals and objectives of parents of handicapped youth;
- Importance of each type of service in relation to the others;
- Past, present, and projected future effect of various services on the quality of life of handicapped children;
- Effect of various services on physical skills, social skills, psychological states, financial states, etc.;
- Suggestions for services and program improvement.

A word of caution: the findings of the survey are based solely on the perceptions of service users, which may sometimes be inaccurate. Parents' attitudes color and may distort their memories of services received. Some parents are grateful for any help that is offered, while others are perennially dissatisfied. In the latter case, for example, a parent may "forget" offers of services if they do not jibe with his own version of the child's needs. Despite these problems, we feel that the views of clients are absolutely necessary in a comprehensive study of the service system, because they are the population the system should serve, and because the agency viewpoint itself is not free of distortions.

The Families

Both parents were present in 69 percent of the families, while only one parent was present in another 21 percent. Grandparents and guardians cared for the other 10 percent of the children.

Most of the children had brothers or sisters. Only 8 percent of them had none, while 18 percent had three or more siblings; in most cases, too, the handicapped child was the only impaired child in the family. The sample was about equally divided between males and females. In two-thirds of the cases, the child's handicapping condition appeared to be stabilized. In 15 percent there appeared to be a possibility that it would become worse, and in 12 percent there appeared to be a chance that it would improve.

Most families were long-term residents of the state in which they were interviewed, four-fifths of them having lived there for at least 10 years.

The particular states chosen provide some variation along an urban-rural dimension. Overall, 25 percent of the surveyed families lived in a rural area and 72 percent were urban or suburban; the remaining 3 percent were persons interviewed in an institutional setting rather than at their homes.

We interviewed approximately equal numbers of families with vision-handicapped children in each state, but the distribution over age categories was uneven (only four such children were under five years of age). The same was true for the hearing impaired, who were mostly in the age groups 6 to 12 and 13 to 17. The replies to a series of questions designed to estimate the functional degree of hearing or vision impairment indicate that we interviewed approximately equal numbers of families with totally blind and partially sighted, and profoundly deaf and hard of hearing children.

Parents' Objectives

Some definable types of parental goals for their handicapped children have emerged. The most ambitious is the wish to help the child "live up to his fullest potential." In this view, expressed by 27 percent of the surveyed parents, the handicap is an obstacle to be overcome—not an insurmountable problem. One mother of a 19-year-old high school senior with very little residual vision remarked that he was able to "make up in intelligence what he lacked in vision." The boy intended to become a scientist and was trying to choose between Berkeley, Caltech, and the Northrop Institute of Technology.

A second parental goal is to help the child "be as much like normal children as possible." Normality is seen as the upper bound of the child's possibilities. One mother of two deaf boys had made a particularly thorough attempt to compare her boys to normal children and to duplicate for them all the experiences of the others. She bought them hearing aids and Vibra-alarm clocks to increase their sensory independence; she encouraged them to have paper routes and other money-making projects; a physical education teacher herself, she enrolled them in an ice-hockey league and helped them engage in other sporting activities. She was eager to have them transferred from a special school for the hearing handicapped into regular schools, and liked the special school they attended because transfer was its goal, too. Thirty-eight percent of the families interviewed indicated that they hoped their children could become as close to normal as possible; this was the most frequently mentioned goal across all disability categories.

A third type of parent seems to have more limited goals for the child. Rather than normality, the parent hopes the child can achieve enough independence—financial and personal—to be a "functioning, if handicapped, member of society." Such parents, 18 percent of our sample, seem to be particularly concerned with instrumentalities like special education and training that they see as a means to the end of independence.

Finally, the least ambitious goal is the wish to help the child "adjust to his handicap," to come to terms with it in the sense of learning to live with it rather than overcome it. Only 8 percent of the parents we talked with seemed to take this view.

One factor that undoubtedly influences parental attitudes is the severity of the handicap. Most adjustment-oriented parents had blind children, while most "full-potential" parents and independence-oriented ones had partially sighted children. Another factor may be socioeconomic status. Upper-middle-class parents empha-

sized full potential, while most middle-class parents hoped their children could be normal. Lower-class parents also hoped for normality, but a sizeable minority were independence-oriented.

INFORMATION ON INDIVIDUAL SERVICES

The families' experiences with and views on individual types of services are discussed next, followed by a digest of their comparisons across the various types of services. The data presented are derived from analysis of the 665 services used by the families interviewed. The types of services discussed are: identification; direction; counseling; medical services; sensory aids and other special equipment; education and special training; vocational training; job placement; transportation; personal care; recreation; and financial assistance.

Identification

The search for needed services for handicapped youth begins with identification of the handicapping impairment. Of the families with older handicapped youth, the age at time of diagnosis was 0 to 5 in two-thirds of the cases, and about 40 percent were diagnosed before the age of one. Of the four categories of handicaps we use, blind youth were identified the earliest: a majority before the age of one, and nearly 90 percent before entering school, probably because the condition is often more obvious than partial sightedness or loss of hearing ability. In contrast, less than one-fourth of the hard of hearing were identified by the age of one, and only about half by the age of five.

Usually the parent was first to notice the impairment. The most frequent sources of initial awareness of the handicap were: nonresponse to aural or visual stimuli (33 percent); unusual behavior, such as repeatedly falling down or inability to speak at a normal age (20 percent); visible impairment (17 percent); and a medical examination (14 percent). Vision impairment was most often readily apparent (35 percent) or physician-detected (22 percent), while hearing impairment was most often detected as a result of nonresponsiveness (45 percent) and only seldom by physicians (8 percent). As mentioned above, several parents of profoundly deaf children were much distressed by their pediatricians' reluctance even to test for deafness, and other children were wrongly diagnosed. Inaction or erroneous action is very serious. Diminished hearing ability during the preschool years can inhibit the development of language and communication skills to such an extent that the child may be unable to overcome the resultant handicap even if services are given to him later.

Late or improper identification was also apparent in the interviews with families of partially sighted and hard of hearing youth. For example, one girl with a 60 decibel (dB) bilateral hearing loss was not identified until she was seven and went for a tonsillectomy, and a partially sighted child was incorrectly labelled retarded.

Pediatricians knowledgeable about hearing problems are especially important because parents turn to them most frequently for advice when an impairment is suspected. General practitioners also serve as initial advisors as do medical specialists in vision or hearing problems. According to our survey, medical professionals were chosen as initial advisors by almost 60 percent of the families; relatives and friends were chosen by about 30 percent.

To sum up our observations: (1) Identification is haphazard—too often a matter of chance, not an organized routine that would give all handicapped youth an early

start on the road to needed services. (2) Very significant numbers of the handicapped, particularly the deaf, are either not identified at an early age or are misidentified as having some other impairment. (3) Physicians, to whom families most often turn when they suspect their child has a problem, are not as well trained or as sensitive to potential handicaps as they might be.

Counseling

Parents expressed their need for four kinds of information and counseling. First, they want to know about the handicap itself: what it is, what causes it, and how it will affect the child's development. Second, they need counseling concerning their children's needs and abilities and what they can do to help; even parents who have already reared several children feel they have to "start all over" with the impaired one, and they need advice on how to go about it. Third, parents and their handicapped children may *both* require psychological counseling. And finally, parents need information about available services. Direction, the fourth information need, will be discussed later in this report.

One-fourth of the families surveyed had used counseling services for their children, and about one-half had received parent counseling. These figures are probably higher than the national average, since in both Massachusetts and Wyoming, agencies providing counseling services actively seek out the visually handicapped; however, comparable service is not provided to the hearing impaired.

Only one parent thought that counseling was a major unmet need for the child; eight others would have used counseling had they known where to ask for it. Only two interviewees thought parental counseling had been a major unmet need; fourteen others would have used it had it been available. About one-third of the families thought they could benefit from counseling in the future.

About half of those counseled thought that the service was *very* beneficial—a high rate, indicating the strong need for advice (especially at the beginning of the child's life). Only 3 percent felt it had no effect.

The families used 78 separate counseling services, about evenly distributed among the states and handicaps. Of these, 18 were offered by private organizations (a notable example is the John Tracy Clinic and its correspondence course for families with hearing handicapped youth), 41 were state services, 4 were from private professionals and 9 were from associations of the handicapped or their parents. Referrals to counselors came from doctors in about one-third of the cases surveyed; about one-fifth were recommendations from schools; about one-tenth came from welfare agencies; and about one-tenth resulted from the parents' own research or the recommendations of other individuals.

Although most of the families that used counseling services found them satisfactory, 10 percent (a rather high rate compared with most other services) were not satisfied. A major criticism was that counseling services were not appropriate to the problems of the child or family. For example, a local PTA had obtained and paid for a psychologist's services for a high-school-age deaf girl. Rightly or wrongly, she was mildly annoyed by his "psychologizing," preferring that he offer her more practical guidance in the choice of a vocational objective. Since a counselor must often deal with the very personal problems of his clients, it is not surprising that he sometimes is perceived as intruding on the privacy of the client. Several persons expressed resentment at "personal questions," and one young divorced mother of a partially sighted and hyperactive boy refused to go back to her counselor because "He told me I was a bad mother." (The families' criticisms, while they deserve to be noted, tabulated, and respected, should sometimes be taken with a grain of salt. Every

counselor is familiar with client resistance, the anger that unpleasant truths can arouse, and the frequent distortion of the counselor's remarks. This is not to deny, of course, that some counselors are inept and that even the good ones can make serious mistakes.) On the other hand, many counselors received rave notices from families that had benefited from their support and advice. A third problem is that the counseling agencies are so understaffed that most families that are served are contacted only once or twice a year.

Medical Services

All but one of the families surveyed used at least one medical server, and 60 percent used two or more. This high usage rate is reasonable since each hearing or vision handicapped youth needs at least to be examined by a physician, probably a specialist, to ascertain if anything can be done to correct or alleviate the impairment, or to prevent further deterioration of sensory ability. In many cases, however, the parents were simply double-checking because they were reluctant to accept one man's diagnosis of a severe and uncorrectable hearing or vision impairment.

Upper-income families used more medical service than did other groups, but lower-income parents used more than middle-class ones did, perhaps because they had better access to public financial aid to pay for treatment.

Of the 131 different medical servers used by families in our sample, 86 percent were "private professionals," while 7 percent were obtained through state agencies (such as the Crippled Children's Service) and 2 percent through charitable sources. About half the doctors were located less than ten miles from the respondents' homes, but more families are willing to travel long distances for this service than for any other: a dozen traveled over 100 miles each way for the service. Medical care is sought more intensively than other services. Although most parents seldom considered more than one source for any other service, fully 25 percent of them considered more than one doctor before making an initial choice. If refused service, respondents almost always continued their search elsewhere.

Eleven families wanted additional medical services, but many of them admitted they were hoping for "a miracle," rather than needing a specific service. However, lower-income families expressed unmet medical needs more often than other income groups and generally cited expense as the reason.

Satisfaction with medical services was lower than for any other service area. Families indicated that 12 percent of the doctors were "not competent" and 11 percent were "not courteous." The commonest complaint was that medical personnel were "impersonal." In several instances university-affiliated hospitals were cited for treating children as cases rather than persons. As discussed above under "Identification," parents complained that pediatricians sometimes disregarded their insistence that something was wrong with their children, especially in the cases of the hearing-impaired. Several other parents complained that physicians diagnosed the problem correctly but were unable to advise the families what to expect of the child or where to go for services to meet his special needs. Of course, comprehensive, nonmedical guidance is neither the doctor's nor anyone else's responsibility in most states. However, when a doctor or another member of a hospital or clinic staff was well informed and offered nonmedical guidance, a much-needed service was performed which the parents later remembered with gratitude. Another problem cited with medical treatment services included transportation to a distant service location (mentioned in one-fourth of the cases of service use).

Financial problems plagued some families, though most regarded the burden as

a "necessary evil." More than half the respondents paid at least part of the cost of the medical care they received (most other services were provided at little or no cost). Forty-two percent of the families received financial assistance from a source other than their own resources or personal insurance to help pay medical expenses. For two-thirds of those who received no such aid, however, medical care was cited as a financial hardship.

Another problem cited was doctors' failure to appreciate the possibility of multiple impairments, a potential difficulty with highly specialized physicians. One mother whose daughter is a national hula-hoop champion despite being aphasic and visually and auditorially handicapped, did not learn about the aphasia until a school psychologist amassed all the medical reports concerning the girl and tried to take an overview of the girl's problems. He was the first to suggest aphasia. Later, the same child was also found to have an allergy that affected her hearing. Shots to combat the allergy have made a significant improvement in her hearing.

All in all, the major problem with medical services does not appear to be in the quantity or quality of the treatment given after diagnosis, but in the diagnosis itself.

Despite these deficiencies, the families regarded 35 percent of the medical services as very beneficial, and about 36 percent as beneficial to a lesser degree. Only 18 percent of the medical services were said to have had no effect on the child, and only 6 percent were thought to have had detrimental effects.

Suggestions for improving medical services included the following: Some medical agency or some one doctor in a group practice should take the responsibility for collecting and evaluating all of each child's medical records. Doctors—especially pediatricians, who are usually the initial advisors of parents with handicapped children—should be sensitized to the possibility of handicapping conditions and to the need for early diagnosis of handicaps such as deafness, and should possess information concerning available services. Doctors should be encouraged, even required, to report impaired children's names to state agencies or associations of the handicapped so that service personnel can get in touch with families. Doctors should be given special training in testing children for handicapping conditions. Finally, several parents stressed their wish that the government would sponsor further research into handicapping conditions. They feared they were "hoping for miracles," but with characteristically American faith in technology, they thought concerted efforts could produce better results, if not cures.

Sensory Aids and Other Special Equipment

All but five families had used at least one sensory aid or equipment service; these included hearing aids and lenses as well as aids for mobility (canes and guide dogs), for reading (braille and talking books), and other equipment (special watches, alarm clocks, tape recorders, slates, toys, etc.). Service use was directly related to income, which accounts for the fact that 30 percent of the low-income families claimed they needed additional equipment, while only 12 percent of the upper-middle-class group expressed similar needs. The expense of equipment was cited by ten parents who thought their needs were not fully met. For essential equipment, such as a hearing aid, parents typically settled for less than the best. Another eight families said that the service or equipment they needed did not exist (they mentioned such things as special amplifiers for TV sets and books for blind toddlers).

Of the sensory aids or special equipment services discussed, 43 percent were hearing aids, 25 percent were reading aids (e.g., braille books and tapes), and 16 percent were lenses or magnification aids. In one-third of the cases families were

referred to the service by their doctor or audiologist. School personnel recommended sensory aids or special equipment in 13 percent of the cases, and state agencies for the visually handicapped accounted for 11 percent of the referrals.

Although commercial dealers were frequently used, parents did little comparison-shopping for either cost or quality. Two-thirds of the time they considered no alternatives, usually selecting a dealer or agency because someone had recommended it, but the next-most-frequent reason was that it was cheaper. In two-thirds of the cases, all or part of the cost of the aid was paid by someone other than the parents themselves.

One-third of the service purveyors were rated very satisfactory, another half were said to be satisfactory, and only one in ten caused dissatisfaction. The aids themselves were rated very beneficial by about two-thirds of the families with partially sighted or deaf children, and by about half the families with blind or hard of hearing children. The most dramatic and glowing praise was given to the change resulting from a hearing aid: one child began to talk for the first time soon after receiving the aid, and another, a 12-year-old, markedly improved his grades after he received his first hearing aid. Only one in ten service users said the sensory aid or other equipment had no beneficial effect.

Several problems were mentioned by the families using sensory aids or other special equipment services. Fourteen percent said they had to wait much too long for service—usually while the bureaucracy processed the request or while hearing aids or braille books were mailed from out-of-town sources. A Wyoming junior-high-schooler did not receive materials for one course until a week before the final test.

A second problem was noted by parents buying hearing aids and corrective lenses. They usually were given insufficient advice about motivating the child to use the aid and for using and maintaining it. Hence, several cases were found of children not benefiting because the aid was in poor repair or because the child refused to wear it. Another problem was selecting an aid and a dealer. Sometimes audiologists would recommend a special brand, but only one dealer specializing in that brand served the area where the family lived. A few respondents felt "at the mercy" of the audiologist's expertise. When a specific type of aid was *not* recommended, however, several parents said they were at a loss to choose. One family applauded their audiologist for recommending a type of aid and discussing with them the dealers in their area who sold various brands. He would not recommend a specific dealer, but he told them which aids were most expensive and which dealers had been criticized by other parents. One parent also noted price-quotations ranging from \$200 to \$385 for precisely the same make and model of hearing aid.

Finally, dealers were occasionally criticized for what parents felt was poor service or improper conduct. Some did not inform parents that state services were available to pay part or all of the cost of the lenses or other aid; others seemed too "commercial," e.g., trying to push the more expensive models of hearing aids. Hearing aid dealers were also criticized for their inability to work well with young children. Aside from the parents' opinions, several cases of poor initial selection of an aid or incorrect fitting of an ear mold attest to the presence of a problem.

Suggestions for improvement included special training or licensing of dealers and the provision of information to parents on the merits and costs of different aids. Parents also advocated wider availability of information on use of the aids and programs to pay for them. Finally, parents hoped for the development of new kinds of equipment, such as individualized amplifiers for the television so that a deaf child could have a higher volume of sound while the rest of the family preserved the integrity of their eardrums, and a quieter braillewriter so blind students could take

notes without disturbing classmates; and for a wider variety of existing equipment, such as more braille and talking books for each age and type of child.

The major message about sensory aids, however, was that they can be extremely beneficial. Consequently, while a few hundred dollars for a pair of glasses or a hearing aid may seem like a great deal, parents believe the cost is reasonable enough in view of the effects they can have on a child's life.

Education and Special Training

Educational and special training services had been used by 69 of 77 families we surveyed. Services included both preschool and regular academic education and the special training needed by impaired children. For the hearing impaired, this usually meant speech therapy, and for the visually impaired, mobility training. As with medical treatment, both upper-middle-class and lower-income families used more services than did middle-class parents. All children who had not been served in any educational program were less than five years old.

Although these handicapped youth went to school, *many received no special education services*. The breakdown by type of educational program was: nursery or preschool, 9 percent; regular class only, in public school, 26 percent; regular class with special equipment, in public school, 4 percent; regular class supplemented by special program for the handicapped, 21 percent; special class for the handicapped only, in public school, 12 percent; residential school, 8 percent; and private school, 7 percent. Deaf youth were most often served in special classes for the handicapped only, or in a regular class only; while hard of hearing youth were most often served in a regular class supplemented by a special program or in a special class for the handicapped only. Blind youth were most often served in a regular class only, or in a residential school; while partially sighted youth were most often served in a regular class only or in a regular class supplemented by a special program.

About one-third of the referrals to educational services came from within the educational system. Another fifth came from doctors and about 30 percent were from counselors, such as those affiliated with state agencies for the visually handicapped, who helped the parents of the more severely handicapped find the right special schools for their children and who were also instrumental, for example, in helping older children find the right vocational training for a post-high-school education.

Most educational services were provided out of public funds, but some—especially preschool or special training—were funded from other sources. Parents themselves paid for 13 percent of the services received, and 7 percent were paid by charitable organizations.

In general, educational services were deemed important and highly satisfactory. Service was typically felt to be sufficient, individualized, offered by competent and courteous personnel, and very beneficial to the youth. The parents of more severely handicapped children tended to give "very beneficial" ratings more often than those of less-impaired youth (80 percent versus 60 percent). Only three families felt the schools were "slightly beneficial," and none said the schools had "no effect."

Several problems were mentioned. One common cause of dissatisfaction was the lack of school programs in the immediate geographic area and the need to send the child to a faraway residential school for most of the year. One result was that parents found it difficult even to visit the child. Another result was that eight families, six of whom had deaf children, had moved expressly to be near a good school for their children.

Another problem related to distance occurred when children had to be trans-

ported daily to special schools; only 61 percent of the students went to school within ten miles of home. Though they lived at home, they could not participate in after-school activities because transportation consumed so much of their free time. One in five students attended a school (including residential schools) more than 50 miles from home.

Parents' views on the curriculum were also noted. One-third of the parents, especially those of blind children and parents of children in residential schools, felt that schools should place more emphasis on the "3 Rs." One-fifth of the parents, usually of the more severely impaired children, thought there should be more attention given to training for activities of daily living. Parents with children in special classes typically thought they were getting enough development of social skills, but only half the parents whose children were in regular classes or residential schools agreed. One blind young man argued that residential schools should do more to encourage a spirit of independence in their students.

Occasionally, educators showed insensitivity to the needs and feelings of impaired children. One girl was, in the opinion of her mother, subjected to subtle ridicule by a teacher who continually pointed out her handicap during classes. We have mentioned the 8-year-old girl who was punished for "disruptive behavior" by having a paper bag placed over her head. Other teachers were said to be too willing to keep the child dependent, or to interpret as misbehavior what was really the result of an impairment—for example, the inattention of a deaf child.

Finally, parents sometimes felt that no available program was exactly right for their children's needs. Some parents of deaf children, for example, found that schools emphasized either the oral or the manual method of teaching to the exclusion of the other. They had to send their children to distant or expensive private schools to get the training the parents felt they needed. Several parents with partially sighted or hard of hearing youth mentioned that the only available programs were designed primarily for blind or deaf youth. In two cases, hard of hearing youth were forced to use sign language instead of talk because they were in a school for the deaf. Two other partially sighted youth were taught to read braille instead of printed type because they were in a class for the blind.

Most parents were satisfied with the amount of education received. Six families were not, all of them families with visually handicapped children; 13 others said they would have used more service had it been available. Because of crowding, 11 families had been refused service at the school of first choice. In Wyoming, some parents said their needs were unmet because the services were unavailable in the geographic area; and in Massachusetts, some parents complained because there was no high school for the deaf in their area. One parent suggested that, at the very least, every state and every major metropolitan area should offer a complete range of educational services for handicapped youth.

Two particular kinds of special training were explicitly considered in the survey: speech training for auditorially handicapped youth and mobility training for the visually impaired. Thirty-four of the 40 families with hearing handicapped youth had used speech therapy services. Nine families were dissatisfied with speech therapy as a service, usually because it was *not available in the interviewee's area*. With adequate hearing aids and speech training, many hard of hearing youth can be educated in the regular classroom, instead of needing more expensive, specialized education programs. Thirteen parents had sought and used mobility training services; most of the recipients were blind, not partially sighted, and most were older children. Unmet needs were felt by four parents of totally blind youth. They were unable to obtain service either because it was not locally available or because the children were too young to be eligible. Some parents noted, however, that the

services really should be offered earlier than they typically are; as one blind girl in California explained, by the time she was given mobility training in high school, her fears and inhibitions had become so ingrained that she was unable to profit fully by it.

Providing relevant information to the parent was another suggested improvement: information on what training programs are available and how to choose among them, and information on how the parent can help in the child's training at home.

Vocational Training

Four of our respondents had received vocational training: two from a public rehabilitation agency and two from private, commercial training schools. Two of them had used vocational training services only, and two others had been placed in jobs by the schools they attended. Vocational training was not regarded as one of the more important service needs. Most families would not even travel to obtain the service.

Unmet needs were expressed by 12 families, who said that services did not exist as far as they knew, or were not available in the area. Thirteen others thought they might need vocational training in the future. Of these, eight planned to seek help from state or local public agencies; however, most said they thought the service would make some difference but not a great one in their children's lives.

Overall ratings of those receiving vocational training included one family that was very satisfied, two who thought the service was satisfactory, and one young blind woman who was not satisfied. She felt that the service was not helpful because little imagination was shown in choosing jobs for which to train blind youth. She had learned to be a darkroom technician but did not like the work, even when she could find it. Of families that had investigated but not requested service, it was thought that the vocational rehabilitation agency's occupational training choices were limited in both number and desirability. One said he had heard the agency would reject deaf persons with poor speech; another said friends had told him "not to use VR" because of the low occupational expectations the counselors have for deaf people.

Job Placement

Only five of the older youth whose families we interviewed had held a regular part-time or full-time job for more than a year. About three-quarters of the 28 youth who had worked at all had had problems; and the majority of those felt their handicap was the major reason.

Despite these problems, only eleven sets of parents in our sample had any contact with placement services. In four of these cases, the service was limited to the provision of information about available jobs, although in one other case the counselor applied in the youth's name. Three of the youth served were offered only counseling or vocational guidance, not actual job placement services. Placement services were not regarded as critically important by any of the families; only one parent would pay for the service if necessary, and only one would travel to obtain it. Three parents who had been unable to find placement assistance felt that it was a "great need," however, and six others would have used the service had it been available. Most who were unhappy with placement services explained that they did not know where to go or said the service did not exist in their area. Of those using placement services, five rated them "very beneficial," while two each thought they were of "some," "slight," or "no effect."

The only suggested improvement was that rehabilitation personnel should act as advocates for the youth or should try to persuade businesses to consider the applications of impaired youth, and then inform the young people of those who were willing.

Personal Care

Only ten families in our sample had used personal care services: four had hired a day nurse at some time or another, and the rest used full-time but temporary babysitters or relatives. Only 5 families said they had ever wished for help in caring for their children but were unable to find it. A few parents thought they might possibly require personal care services in the future, but only one of them thought getting the service would make a "great difference." In brief, the families felt that they were capable of meeting the personal care needs of their visually or aurally handicapped youth.

Recreation

One-third of the families surveyed had used recreation services of some sort, usually parties, summer camps, and field trips. Almost two-thirds of the blind children had used at least one recreational service, but only 40 percent of the partially sighted, 24 percent of the deaf, and 10 percent of the hard of hearing had done so. This was partly the result of service availability; although 68 percent of the blind children had been offered recreational services, only 45 percent of the partially sighted, 38 percent of the deaf, and 26 percent of the hard of hearing had received offers.

A significant minority of the parents felt that their children needed more opportunities to interact with peers. Recreational service users were mostly from this group; perhaps these services are sought to fill in perceived gaps left by schools and neighborhood activities. About half the families said they would use more recreational services if they were available. Two-thirds of the rural residents cited unmet recreational needs, mostly because the services were not offered in their area. Urban and suburban respondents thought the services were probably available, but they did not know where to ask about them.

Of the 26 recreation services used, about half were provided by charitable organizations, with associations of the handicapped the next largest source. Most of the families did not regard recreation as a critical need, but those who used services were well satisfied with them. They praised two results of the services: their children learned to be more independent, and they met new friends.

Two problems with recreational services were noted. For children who attend residential schools or special programs in public schools, organized recreation cuts into their time with their families. Parents whose children are away in school all year are loath to part with them in the summer. Second, participation in recreational programs tends to decrease opportunities for play with normal children in the neighborhood. (On the other hand, for children in public schools, recreational programs for handicapped youth provided needed opportunities to interact with other children like themselves.) Some parents felt that programs should be devised to provide a mixture of handicapped and normal children.

Transportation

Thirty-five of the families surveyed had used some sort of transportation service, mostly school bussing. Only one-third of rural residents were getting transportation

service, compared with about half of those living in urban or suburban areas. Of the 48 separate transportation services used, one-third were offered by state agencies and one-third by local school districts. Charitable organizations, such as the Foundation for the Junior Blind in California, supplied 16 percent. As with information about many other services, knowledge of programs supplying transportation was more often a matter of luck than routine dissemination of the information. One Massachusetts mother walked a mile with her five-year-old blind daughter to school each day because she did not have a car and no bus service was available. Pregnant and near the end of her term, she began to worry that she would have to send the little girl to school alone. Finally, she asked a teacher at the school what to do, and the teacher offhandedly replied that she should "use the taxis." The mother knew she could not afford that, so she worried for a few more days. At last she mentioned her problem to another mother, who informed her that the state provided free taxi service to school for handicapped children. She thought the school should make a systematic effort to inform parents of handicapped children about the range of services available to them.

Quite a few families were willing to fight for transportation service if refused it. Not long before the interviews were conducted, a new director of educational services for the handicapped was appointed in Massachusetts. One of his first acts in office was to cut back transportation services, whereupon an army of enraged parents camped on the Capitol steps. As a result the level of service to many was reinstated.

One-third of the sample said they had experienced unmet needs for transportation. About 60 percent of the rural families had had transportation problems; urban and suburban families also cited problems in about a third of the cases. Transportation difficulties resulted in a general reduction in the use of other services for 10 percent of the families surveyed.

Although most families managed to find transportation to other needed services, many of them faced problems in doing so. Since the handicapped population is widely distributed geographically, many of them must travel long distances for services, and this imposes numerous costs. Often the parent must pay for the service itself; he must also pay his own transportation and living costs if, say, medical care is offered in a distant city; and he sacrifices time that could be spent with other children or even at work. Several fathers had to arrange days off to drive their children to hospitals.

Transportation to the point at which other services are provided has been a problem cited many times before in our discussion; the reason it is such a problem is that the handicapped population is dispersed widely, while service agencies often are not. That is, transportation is not a problem primarily because the youth are handicapped, but because the service agencies are located as they are.

Financial Assistance

Fifty-six percent of the families surveyed had received financial aid either directly or to purchase other specific services.

A total of 51 financial services were used, of which 10 percent were private charities and the rest were public assistance of some sort, split about equally between hearing and vision impaired youth. The volume of funds expended is not known. In 6 percent of the cases, the aid was an income supplement, 8 percent of the time it represented full or partial payment of school tuition, 28 percent of the cases were for medical bills, 14 percent paid for special equipment, and 28 percent of the cases were for more than one of these purposes. In addition to funds, some

counseling was provided in about one-third of the cases. These figures do not include cases of the direct provision of service such as schooling, when no financial reimbursement is involved.

Almost one-third of the respondents said they would have liked more financial assistance, and in 9 percent of the cases it was expressed as a major need. One-third of those who expressed needs said they did not know where to ask for help, and another third had been refused financial aid.

About half the sample thought their children might need financial assistance in the future—10 percent were fairly certain they would.

A few problems with financial aid services were cited. A few people had experienced difficulty or delay in arranging payment of medical or special equipment services through state agencies. A few wished that a wider range of services could be provided—such as transportation to a medical or educational service facility, or additional equipment. But most users of financial assistance were delighted to have it, and three-quarters of them thought it sufficient for their needs. Two families charged discrimination in that the blind get an extra income tax deduction while the deaf do not. One family did not take full advantage of needed speech therapy service because they couldn't afford it and did not know the state would assist them. Several families expressed displeasure at having to accept funds labelled as "welfare," and were displeased with the quality of welfare agency personnel.

One suggestion for improving the financial aid service was to develop a special definition of indigency for parents with handicapped children, much as the Medicaid program has a "medically indigent" classification that includes more persons than the "indigent" classification does.

DIFFICULTIES WITH INFORMATION ON THE SERVICE SYSTEM

Once a handicapped child has been identified, he or his family needs to know what mix of other services is needed and where to obtain them. The determination of the appropriate mix of services and service providers is what we call *direction*. Only one-third of the families said they had experienced no difficulties in finding appropriate services; another third reported some problems, and another third had had many problems. Parents of hard of hearing and partially sighted children were far more likely to have experienced "many problems" than were parents of blind or deaf children. Gaps in the services available were reported by 60 percent of the families. Only 40 percent were fully pleased with the sufficiency or overall amount of services received, and families with preschool handicapped children or less severely handicapped children felt the least satisfied. Slightly less than half the families interviewed were fully pleased with the appropriateness of the package of services delivered to them; that is, they felt they were "offered the right kinds of services." The families with less severely handicapped youth, or preschool handicapped youth, or hearing handicapped youth were least likely to be fully pleased with the appropriateness of services. Thus, more than half the families reported problems with direction to various services: most reported gaps in the services provided, lack of full satisfaction with the sufficiency of the services provided, and lack of full satisfaction with the appropriateness of the mix of services. Direction is clearly a major problem.

Parents generally reported lack of information about what services are available, and where to obtain them. As one parent put it, "There are so many government agencies, the people don't know *where* to go." Another frustrated parent made

an excellent point: "I don't even know what questions to ask." Many reported a "chain of talking and talking and talking" and of referrals "from place to place to place" until, with persistence and much "stumbling around," they found someone who could tell them where to get the needed services. Others were simply lucky, as when a speech therapist accidentally met a deaf child in need of help in a furniture store. In general, however, no one had either the information or the responsibility to help the parents plan an appropriate mix of services and direct them to the service providers. Two notable exceptions are the Division of Services to the Visually Handicapped in Wyoming and the Commission for the Blind in Massachusetts. A good direction program could also eliminate much unnecessary retesting of children by various service providers who presently do not have easy access to each other's test results.

Parental persistence and tediously acquired knowledge of available services clearly made a difference in what the child received. For example, the most services we observed being received by a single family went to a deaf child who lived in a foster home with 11 other children (8 of them multihandicapped) and with two very experienced, savvy, and persistent foster parents.

SUMMARY: PARENTAL SATISFACTION WITH THE SYSTEM AND INDIVIDUAL SERVICES

Overall Satisfaction with and Benefits of the Service System

Finally, parents were asked to give their views on their general satisfaction with the service system, and their general assessment of how much their child had benefited from the package of services received.

Forty percent of the families said they were very satisfied with the overall system; about half said they were satisfied, but not completely; and 5 percent said they were definitely not satisfied. Parents of younger children and of less severely handicapped children were least likely to be satisfied.

In assessing the degree to which the service system benefits handicapped youth, 62 percent of the respondents thought the services had been very beneficial on the whole, 24 percent thought they were somewhat beneficial, and 14 percent were convinced the service system had had little or no benefits. Within the majority of parents who felt the overall service effects were very beneficial, however, there were significant variations by type of handicap (67 percent for the hearing impaired versus 57 percent for the vision impaired), and by age (70 percent for 18- to 21-year-olds versus 54 percent for children 0 to 5 years old).

Relative Importance of Individual Services

As we have seen, the parents rated both individual services and the system as a whole as to their overall satisfaction, the competence and courtesy of the personnel, and each service's benefit to the youth. A summary look across the services is presented here.

Parents were fully satisfied with 38 percent of the individual services delivered, partially satisfied with 49 percent, and dissatisfied with 13 percent. The three services they considered most important were education, sensory aids, and medical treatment. Of these, educational services received the most "very satisfied" ratings, and medical services the fewest. Similar findings characterized personnel ratings:

though very few service agencies of any sort were said to have discourteous or incompetent staff, medical servers and special equipment dealers received more uncomplimentary ratings than did other servers, while medical servers and educators received more "very good" ratings than did other servers. Educational services were given the most "very beneficial to the youth" ratings, with sensory aids and medical treatment following.

Several questions were asked to determine the relative importance of various services to parents. One question was what they thought to be their preeminent service need at the time of the survey. Education was the overwhelming first choice across all categories of parents, followed by special equipment and medical service. We emphasize that these rankings are of *current* need, not of needs throughout the child's lifetime. The remaining services were, in decreasing order of rated importance, vocational education, financial aid, transportation, job placement, counseling, and recreation. We did not ask the interviewees to rate the identification or direction services.

As another measure of importance, we asked parents if they had undergone financial hardship to obtain any services. Two-thirds of those who said yes had done so for medical treatment, about one-fifth for sensory aids, and one-tenth for education. When asked what services they would pay more for if necessary, the three mentioned the most often were education, medical service, and sensory aids. Parents were also asked whether they would be willing to relocate to obtain any particular service. Nearly all of those who *would* move would do so for medical treatment or education; three families *did* move to obtain better medical service, and eight moved to obtain educational services. Of all the services, parents were most willing to travel to obtain medical treatment or sensory aids, and to obtain education (although they strongly preferred to have their children attend schools near home). They said they would not, and did not, travel far to obtain the other services.

Finally, we asked what strategies parents would use if refused a specific service. Summing the responses for all types of services, 85 percent would "continue the search," 9 percent would "fight," and 7 percent would "forget it." Most of those who would "fight" would do so for educational services; those who would "continue the search" would seek medical treatment, sensory aids, or education; and those who would "forget it" were speaking of transportation and recreation services.

Appendix A
INTERVIEW GUIDE FOR HANDICAPPED YOUTH SURVEY

This appendix contains the interview guide used in our person-to-person survey of families with hearing or vision handicapped youth. Schedules A through D were not followed precisely during any interview, but rather served as a topic guide; where desirable, topics were added or deleted. The written schedules were never given to the interviewee, and the questions evolved and were adapted from the initial version printed in this appendix to reflect the interviewer's experience and the respondent's particular situation. Cards A and B were given to respondents to help them express and quantify their subjective opinions on the value of various programs and services.

State: _____

Type Disability: _____

The Rand Corporation is a nonprofit organization that does research on various subjects. In this project we are trying to help the Department of Health, Education and Welfare evaluate its programs for children whose hearing or vision is impaired. We want to know how well those programs are working, so that the government can improve them or devise new ones; and therefore we need to know the opinions and experiences of people who have used those services. The people on this project do not work for the Department of Health, Education and Welfare or any other government agency, however. We work for a private research organization.

Because we want to know about your experiences and opinions in some detail, it may take quite some time to answer all the questions. I hope you won't mind, because the information you can give us is very important.

I want to assure you, too, that The Rand Corporation will not be putting your name in any published report, so we hope you'll feel free to be perfectly candid.

I'd like to begin by asking some questions about the sorts of things you might have felt a need for as a result of your child's special problem. I'm interested in finding out about what you have needed in the past and what you need now (even if you're not able to get it)--and also what sorts of things you expect you might need as your child gets older.

Incidentally, when I talk about "services" or "service agencies," I have in mind *any* place you go to get the things you need--government agencies, associations of the handicapped, private doctors or clinics, regular or special schools, anything.

- a. First, what is the child's name?
- b. How old is he (she)?
- c. How many other children are in your family?
- d. What are their ages?
- e. Do any of them have impaired hearing or vision?

I-1 MEDICAL TREATMENT

1. Has your child had medical treatment specifically for his vision or hearing problem?

(INTERVIEWER PROBE)

- testing and evaluation (how often?)
- past treatment
- current treatment (how often is it needed?)
- type of medical or surgical treatment

2. (IF YES) Where do or did you go to get this treatment? (FILL OUT SCHEDULE A OR B.)

3. Has there ever been medical treatment that you thought you might have needed but for some reason could not or did not get?

4. DIAGNOSIS AND SCREENING

- a. What sort of vision/hearing impairment does your child have? Do you know the medical name of the problem?
 - b. When did you first find out that he had vision/hearing problems?
 - c. How did you find out?
 - d. Did you ask for or did anyone give you advice about what to do?
 - e. What did you decide to do? Why?
 - f. What is the probable future course of the impairment? Will it become better, worse, or stay the same?
5. Will your child need medical treatment for his impairment in the future? (IF YES, FILL OUT SCHEDULE C.)

I-2 SPECIAL EQUIPMENT

1. Has your child ever used special equipment to aid his hearing or vision?
 - eyeglasses
 - telescopic or microscopic lens systems
 - hand or desk-mounted magnifiers
 - closed circuit TV systems
 - large print books
 - tapes
 - canes
 - guide dogs

 - hearing aids (body)
 - hearing aids (ear)
 - special alarm clocks
 - telephone amplifiers

 - other (SPECIFY)

2. (IF YES) Where did you go to get this special equipment? (FILL OUT SCHEDULE A OR B.)

3. Was there ever any special equipment that you thought you might have needed but for some reason could not or did not get?

4. Is there any special equipment that you think your child might need at some time in the future? (IF YES, FILL OUT SCHEDULE C.)

I-3 PERSONAL CARE

1. Have you ever had to hire someone to take care of your child's day-to-day needs relative to personal care?

2. (IF YES) Where did you go to get this service? (FILL OUT SCHEDULE A OR B.)

3. Have you ever felt that you needed someone to help you care for your child's personal needs but for some reason could not or did not get this help?

4. Do you think your child will, at some future time, need someone to help him take care of his personal needs? (IF YES, FILL OUT SCHEDULE C.)

I-4 EDUCATION

1. Let's talk for a moment about your child's education. Does he go to school? (IF YES, FILL OUT SCHEDULE A OR B.)

(INTERVIEWER PROBE)

- residential school (public or private?)
- self-contained classes
- tutoring
- special classes in addition to regular school program
- regular school (public or private?)
- regular school with special equipment (what equipment?)

2. What grade is he in?
3. Do you know whether there is a program at his school to test the vision and hearing of the children? At what age are they tested?
4. (FOR DEAF/HARD OF HEARING ONLY) Is your child receiving speech therapy?
5. Have you ever felt that your child could have used some special education or training that for some reason you could not or did not get?
6. Would you like to see more emphasis, less emphasis, or the same emphasis in school on any of these areas:

More Less Same

- a. Reading and writing _____
- b. Speech _____
- c. Mobility (getting around at home, in the city) _____
- d. Vocational training, job training _____
- e. Activities of daily living _____
- f. Social skills, getting along with others _____

7. What sort of future educational needs will your child have?

(INTERVIEWER PROBE)

- college? where?
- learning to cope with his handicap? (IF YES, FILL OUT SCHEDULE C.)

I-5 VOCATIONAL TRAINING

1. Has your child had any special job training?

(INTERVIEWER PROBE)

- in regular school
- in vocational school
- special education classes in regular school
- in vocational school for the handicapped
- in sheltered workshops

2. (IF YES) Where did you go to get this training? (FILL OUT SCHEDULE A OR B.)
3. Is there any special work-related training that you thought might have been useful for your child but that for some reason you could not or did not get?
4. Do you think your child will need vocational training at some time in the future? (IF YES, FILL OUT SCHEDULE C.)

I-6 PLACEMENT

1. Has your child ever wanted to find part-time or full-time work?
2. (IF YES) Did he have any trouble finding work?
3. Was his difficulty in finding work related at all to his impairment?
4. Did his teacher at school or his vocational training counselor try to help him find the job?
5. Did he use a placement service?

(INTERVIEWER PROBE)

___ for normal persons

___ for handicapped persons

(IF YES, FILL OUT SCHEDULE A OR B.)

6. WORK EXPERIENCE

- a. Has your child ever held a full-time or part-time job?
(What fraction of time?)
 - b. What sort of job(s)? Was he paid?
 - c. How long did he work there?
 - d. Did he have any difficulty on the job that you think was the result of his impairment?
 - e. Did he like the job?
 - f. Why did he leave the job?
7. Do you think your child ever needed job placement services that for some reason you could not or did not get?
 8. Do you think your child will need job placement services in the future? (IF YES, FILL OUT SCHEDULE C.)

I-7 COUNSELING

1. Have you or your child ever used counseling services to help understand the problems connected with hearing or vision impairment?
 visit by social worker of any sort?
 visit by agency personnel?
2. Where did you (or he) go to get these services? (FILL OUT SCHEDULE A OR B.)
3. Have you or your child ever felt the need for counseling but for some reason you could not or did not get it?
4. Do you think you or your child will need counseling at some time in the future? (IF YES, FILL OUT SCHEDULE C.)

I-8 TRANSPORTATION

1. Have you ever received help transporting your child to his classes, doctor, etc.?
 (INTERVIEWER PROBE)
 What is the farthest you've ever had to go to get some service?
 What sort of transportation do you usually use to get to service agencies?
 own auto
 friend's or relative's auto
 public transportation
2. Has a service agency ever offered or given you help in transporting your child or yourself to the agency? (IF YES, FILL OUT SCHEDULE A OR B.)
3. Have you ever wanted help transporting your child to an agency but for some reason you could not or did not get that help?
4. (FOR BLIND OR PARTIALLY-SIGHTED ONLY) Has your child ever received mobility training? (IF YES, FILL OUT SCHEDULE A OR B.)
5. Have you ever had to do without some service altogether, or get less service, because you could not get to the agency?
6. Do you think at any time in the future you will need help transporting yourself or your child to a service agency? (IF YES, FILL OUT SCHEDULE C.)

I-9 RECREATION

Let's talk a bit about your child's social and recreation needs.

1. Does he often have a chance to meet and play with persons his own age? How often?

(INTERVIEWER PROBE)

normal children?
 children with similar impairments?

2. Does your child belong to any clubs or youth groups? Church groups? Community organizations? How many? Which ones?

3. Does your child participate in any sports? What sports? How often?

(INTERVIEWER PROBE)

with normal children?
 with special allowances for his handicap?
 with other children who have impairments?

4. Has any service agency or organization of the handicapped ever offered a program to provide your child with special opportunities for socializing with others, either normal or handicapped? (IF YES, FILL OUT SCHEDULE A OR B.)

5. Have you ever felt that your child needed more opportunities for recreation or socializing that for some reason he could not or did not get?

6. Do you think your child will experience special social or recreational needs in the future? (IF YES, FILL OUT SCHEDULE C.)

I-10 FINANCES

1. Have you ever received help financing your child's special service needs?
2. Where did you go to get this help? What portion of the cost is paid by each source--some, most, all?
 friends or relatives
 bank loan
 welfare programs
 other
3. Have you ever needed help with financing these service needs that for some reason you could not or did not get?
4. Do you think that, at some time in the future, you will need additional help financing your child's special service needs?
5. Do you think your child, at some point in his life, will need financial help providing either for his daily needs or for his special service needs?

II-1 RANKING OF NEEDS

1. We have been talking, now, about ten different kinds of needs that you or your child might have felt. Looking at the list again (INTERVIEWER SHOW CARD B), could you tell me which is your most important need right now--that is, getting or not getting which of these things would make or does make the most difference in your child's life?

Medical treatment
 Special equipment
 Personal care
 Education
 Vocational training
 Job placement
 Counseling
 Transportation
 Recreation
 Financial aid

2. Which service need would you rank second? Third? Last?

3. On a scale of 1 to 10 (INTERVIEWER SHOW CARD B), how important has each service been for your child? A rating of 0 might mean that the service has had no effect on the quality of his life, while a rating of 10 would mean it has had a very beneficial effect.

Medical treatment	0	1	2	3	4	5	6	7	8	9	10
Special equipment	0	1	2	3	4	5	6	7	8	9	10
Personal care	0	1	2	3	4	5	6	7	8	9	10
Education	0	1	2	3	4	5	6	7	8	9	10
Vocational training	0	1	2	3	4	5	6	7	8	9	10
Job placement	0	1	2	3	4	5	6	7	8	9	10
Counseling	0	1	2	3	4	5	6	7	8	9	10
Transportation	0	1	2	3	4	5	6	7	8	9	10
Recreation	0	1	2	3	4	5	6	7	8	9	10
Financial aid	0	1	2	3	4	5	6	7	8	9	10

(IF "0", INTERVIEWER PROBE)

no effect, or negative?
 how negative?

II-2 GENERAL EVALUATION OF SERVICES

1. Overall, have you been pretty well satisfied with the services that you have been offered or have been able to get?

(INTERVIEWER PROBE)

- Have you been able to get enough service usually?
 - Have you been offered the right kinds of services--tailored to your own special needs?
 - Were the services worthwhile? Or a waste of time?
 - Anything else?
2. Overall, do you think the services you have used have improved the quality of your child's life? How much difference have they made? (SHOW CARD A.)
 3. Overall, do you think the services you have used have improved the quality of life for your whole family? A lot or a little? In what ways?
 4. Overall, how much difficulty have you had finding out what services are available and where to go to get them?

II-3 ROLE OF GOVERNMENT

There are a number of different ways in which the government can help people with impaired vision or hearing get the services they need. I'd like to ask your opinion of some of them.

1. Would you like an insurance-type system (like Social Security or unemployment insurance) where everyone pays in, and then those who are impaired by an accident or from birth get the services they need?
2. Would you like getting vouchers from the government to get services from a private or public source of your own choosing?
3. Would you like the government to provide you only with information about where to go for various services (but not to provide the services or pay for them)?
4. Would you prefer getting services from groups that are not connected with the government--like doctors or private clinics--rather than from the government?
5. Are there any areas where you think the government should get out of the business of providing services?

III-1 SEVERITY OF IMPAIRMENT (VISUAL)

1. Is your child classified as legally blind?
2. Is he totally blind in one eye? Or in both eyes? Any residual vision?
3. Does he wear glasses?
4. Can he walk in unfamiliar surroundings without help?
5. Can he walk in unfamiliar surroundings using a cane or guide dog?
6. Can he walk in unfamiliar surroundings only if a sighted person helps him?
7. Can your child read and/or write yet?

(INTERVIEWER PROBE)

- Braille
- regular print
- large print
- handwriting
- typewriting

8. If so, what sorts of visual aids does he need in order to do so?
9. What is his primary method of reading? Does he use tapes, talking books, or a sighted person who reads to him? (IF YES) How often does he use these aids?
10. Can he recognize a familiar face? From how far away?
11. Can he discern light and shadow? Color?
12. Can he watch movies? TV? Sports events?
13. Does he seem to get along well with other children his own age?

IV-1 SEVERITY OF HANDICAP (HEARING)

1. Is your child's hearing impairment
 - mild?
 - moderate?
 - severe?
 - profound?

2. Do you know the decibels (dB) of hearing loss?

3. How well can he understand speech using his hearing only (without lip reading, but with a hearing aid if necessary)?
 - can understand most words and sentences
 - can understand a few words and phrases
 - can understand a few sounds and occasional words

4. Is your child able to talk?
 - relatively easy to understand
 - can say a few phrases
 - can say a few words
 - can make nonverbal sounds
 - cannot speak

5. Did your child learn to speak before his hearing was impaired?

6. Does your child read lips? How well?

7. Does your child use sign or finger spelling? (IF YES) On an ordinary day, how often does he use sign or finger spelling as compared with speaking?

8. Does his hearing problem make it difficult or dangerous for him to get around in unfamiliar surroundings?

9. Does your child enjoy movies? TV? Sports events?

10. Does he seem to get along well with other children his own age?

IV-2 And now, a few wrap-up questions:

1. How many persons live here with you?

2. How many children? How many adults?

3. How long have you lived in this residence?

4. Where did you live before that? For how long?

Interview Number _____

V-1 FOR INTERVIEWER TO FILL OUT

1. Respondent's address: _____
 Street or RR No.

 City, Town, etc.

 County State Zip code
2. Respondent's area: _____ Urban _____ Suburban _____ Rural
3. Respondent's sex: _____ Male _____ Female
4. Respondent's age: _____
5. Respondent's race or ethnic background: _____ Black
 _____ Indian
 _____ Oriental
 _____ Spanish American
 _____ White
 _____ other (SPECIFY) _____
6. Cooperativeness during interview: _____ mostly uncooperative
 _____ sporadically uncooperative
 _____ mostly cooperative
7. Interruptions during interview: _____ many
 _____ a few
 _____ none
8. Others present during part or all of interview:
 _____ respondent alone
 _____ child(ren)
 _____ husband or wife
 _____ other (SPECIFY) _____

9. Interviewer's assessment of parent's attitude toward handicap:

10. Interviewer's assessment of parent's socioeconomic status:

_____ Educational level of respondent

_____ Educational level of spouse

_____ Occupation of respondent

_____ Occupation of spouse

_____ Income

_____ Class ranking

Interview Number _____

Schedule A

SERVICES CURRENTLY IN USE

1. What is the name of the agency?
2. Where is it located (city)?
3. When did you first go there?
4. How often do you go?
5. What services do you get from them?
6. What happens when you go to the agency? (GET RESPONDENT TO PAINT A VERBAL PICTURE OF HIS EXPERIENCE AT THE AGENCY.)
7. What is your impression of agency personnel?
(INTERVIEWER PROBE)
 competent
 well trained
 considerate
 fair
8. Does your child go with you to this agency? (IF YES) Does he like going?
9. On a typical visit to the agency, how much time do you spend there?
10. How much of this is time spent by agency personnel with your child? How much of it is time spent with you?
11. How did you find out about this agency?
 self
 other individual
 physician or optometrist
 hospital
 media
 welfare agency
 school
 association for the handicapped
 counselor
 other (SPECIFY)

Schedule A - Page 2

12. Did you have to do a lot of searching and asking around in order to find out about the agency?
13. Was it difficult to locate and get to the agency?
14. Did you have to wait a long time for an interview?
15. Did you have to wait a long time for service?
16. Before you went to the agency, did you consider any other ways of getting this service? (IF YES) Why did you select this agency over the others?
17. Were you ever refused service by a similar agency? (IF YES, FILL OUT SCHEDULE D.)
18. If you had been refused service at this agency, what do you think you would have done?
19. Do you have to pay anything for the service? Approximately how much?
(IF YES) Does it mean a financial hardship for you?
(IF YES) Would you be willing to pay more for it if you had to?
(IF NO) Would you still use this service if you had to pay for it?
(IF NO) Did you have to take a means test in order to qualify to receive the service?
20. If the service were not offered in this city, would you move to another city in order to get it? Did you move in order to get it?
21. How much has the service helped your child? (INTERVIEWER SHOW CARD A.)
 - physical skills
 - communication skills
 - education, training
 - social skills
 - psychologically (self-confidence, happiness)
 - income
 - ability to see or hear
 - mobility

Schedule A - Page 3

22. If for some reason you had not been able to get this service, how much difference would that have made in your child's life? (SHOW CARD A.)
23. Has the service been helpful or useful to you in any way?
24. Is the service you're getting pretty much what you expected when you first went to the agency?
25. Do you feel that the service was pretty much what you individually needed?
26. Were you offered any service that you didn't want or need?
27. Do you feel you're getting enough service? Would you like more? How much more?
28. Would you like less service? How much less?
29. In general, do you feel satisfied with the service received?
30. Is there anything in particular that you don't like about the service or the agency.
31. Is there anything in particular that you especially like about the program?
32. If you could change the program in any way that you wanted to, what would you do?

Interview Number _____

Schedule B

SERVICES USED PREVIOUSLY

1. What was the name of the agency?
2. Where is it located (city)?
3. When did you first use their services?
4. How often did you go there?
5. How long did you continue using them?
6. What services did you get from them?
7. What happened when you went to the agency? Describe it for me.
8. What was your impression of agency personnel?
(INTERVIEWER PROBE)
 competent
 well trained
 considerate
 fair
9. Did your child go with you to this agency? (IF YES) Did he like going?
10. On a typical visit to the agency, how much time did you spend there?
11. How much of this was time spent by agency personnel with your child, and how much was time spent with you?
12. How did you find out about the agency?
 self
 other individual
 physician or optometrist
 hospital
 media
 welfare agency
 school
 association for the handicapped
 counselor
 other (SPECIFY)

Schedule B - Page 2

13. Did you have to do a lot of searching and asking around in order to find out about the agency?
14. Was it difficult to locate and get to the agency?
15. Did you have to wait a long time for an interview?
16. Did you have to wait a long time for service?
17. Before you went to the agency, did you consider any other ways of getting this service?
18. Were you ever refused service by a similar agency? (IF YES, FILL OUT SCHEDULE D.)
19. If you had been refused service at this agency, what do you think you would have done?
20. Did you have to pay anything for the service? Approximately how much?
- (IF YES) Did it mean a financial hardship for you?
- (IF YES) Would you have been willing to pay more for it if you had to?
- (IF NO) Would you still have used this service if you had had to pay for it?
- (IF NO) Did you have to take a means test in order to qualify to receive the service?
21. If the service had not been offered in your city, would you have moved to another city in order to get it? Did you move in order to get it?
22. How much did the service help your child? (INTERVIEWER SHOW CARD A.)
- ___ physical skills
 ___ communication skills
 ___ education, training
 ___ social skills
 ___ psychologically (self-confidence, happiness)
 ___ income
23. If for some reason you had not been able to get this service, how much difference would it have made in your child's life? (SHOW CARD A.)

Schedule B - Page 3

24. Was the service helpful or useful to you in any way?
25. Was the service you got pretty much what you had expected when you first went to the agency?
26. Was the service pretty much what you individually needed?
27. Were you offered any service that you didn't want or need?
28. Did you feel you got enough service? Would you have liked to have more? How much more?
29. Would you have liked less service? How much less?
30. In general, were you satisfied with the service you received?
31. Was there anything in particular that you didn't like about the service or agency?
32. Was there anything in particular that you especially liked about the program?
33. If you could change the program in any way you wanted to, what would you change?
34. Why did you stop using the service?

Interview Number _____

Schedule C

PROJECTED SERVICE NEEDS

1. Where do you think you will go to get these services?

(IF YOU DON'T KNOW) How would you go about trying to find out where to go?

(IF YOU DO KNOW) Is there any particular reason you would go there instead of some other agency?

2. If you cannot get these services for some reason, do you think it will make a big difference in your child's life?

3. How will these services be paid for?

Card A				
-1	0	1	2	3
Harmful Effect	No Effect	Slightly Beneficial Effect	Beneficial Effect	Very Beneficial Effect

Card B	Not Bene- ficial	Slightly Beneficial			Beneficial			Very Beneficial			
	0	1	2	3	4	5	6	7	8	9	10
___ Medical Treatment	0	1	2	3	4	5	6	7	8	9	10
___ Special equipment	0	1	2	3	4	5	6	7	8	9	10
___ Personal care	0	1	2	3	4	5	6	7	8	9	10
___ Education	0	1	2	3	4	5	6	7	8	9	10
___ Vocational training	0	1	2	3	4	5	6	7	8	9	10
___ Job placement	0	1	2	3	4	5	6	7	8	9	10
___ Counseling	0	1	2	3	4	5	6	7	8	9	10
___ Transportation	0	1	2	3	4	5	6	7	8	9	10
___ Recreation	0	1	2	3	4	5	6	7	8	9	10
___ Financial aid	0	1	2	3	4	5	6	7	8	9	10

Appendix B

STATE VARIATION IN WELFARE PROGRAMS

In Chapter 10 we noted the large variation across states in expenditures and in the number of handicapped persons in Aid to the Blind (AB) and Aid to the Permanently and Totally Disabled (APTD) programs. Although these two programs have been superseded by the Supplementary Security Income program, it was felt that an attempt to explain the wide interstate variations might prove fruitful for planning future open-ended programs. Most of the programs discussed in this report are closed-ended, i.e., the maximum amount to be received by the states from the federal government is set at some specified amount. Under AB and APTD, however, federal expenditures per person receiving aid are specified by a formula, but total program expenditures are "open-ended" in that no ceiling is placed on the number of persons receiving assistance.

This appendix examines factors that may influence these open-ended AB and APTD expenditures. Some past attempts to model and study the determinants of government expenditure patterns are reviewed. The more promising of these models are then tested with data for AB and APTD and found to be of only very limited value as aids to understanding these programs. Finally, we formulate and test a simultaneous equation model. These efforts also led to only limited success in "explaining" the interstate variation. We conclude that the determinants of state and federal expenditures for financial assistance to handicapped persons under the AB and APTD programs are too complex to be well understood using currently available data and econometric models.

REVIEW OF LITERATURE

The original article in the discussion of factors affecting interstate differences in the level of government expenditures was written by Fabricant in 1952.¹ He examined, in a multiple regression model framework, the determinants of state and local governmental expenditure patterns for 1942. The expenditure patterns were "explained" in terms of income, degree of urbanization, and population density.

The publication by the United States Bureau of the Census of extensive data on expenditure patterns by state and local governments, particularly the 1957 Census of Governments, provided the impetus for an expanded look at this field. While early studies attempted to replicate the Fabricant findings, work by Sacks and Harris² made a substantial contribution by raising the issue of the role of federal aid in determining state and local expenditure patterns. In effect, this article changed the focus of work in this field. Previous studies concentrated on the issue of explaining and predicting state and local expenditure patterns. With the introduction of federal aid as a major explanatory variable the analysis became more policy relevant. As

¹ Solomon Fabricant, *Trend of Government Activity in the United States Since 1900*, National Bureau of Economic Research, New York, 1952, pp. 122-131.

² Seymour Sacks and Robert Harris, "The Determinants of State and Local Government Expenditures and Intergovernmental Flows of Funds," *National Tax Journal*, Vol. 17, March 1964, pp. 75-85.

Bahl and Saunders³ noted, determinants studies have provided an objective test of the capability of federal matching shares to achieve minimum national standards at lower federal tax costs. The Sacks and Harris approach was extended in 1966 by Osman.⁴ Osman developed a model which he said enabled one to estimate whether or not federal aid was stimulative or substitutive in its effects on state and local expenditures. In addition, he considered the cost effect of federal aid in one area on expenditures in a seemingly unrelated area. The basic model used by Sacks and Harris and by Osman had as its dependent variable total expenditures by state and local governments for a given function, and included federal aid among the independent variables. This approach was criticized by several authors on at least two grounds. First, regressing total expenditures which included federal aid against federal aid would, in fact, create a biased result (for example, see Morss).⁵ Second, the direction of causality was not clear and it was quite possible that instead of federal aid explaining state and local expenditures, state and local expenditures, because of the open-endedness of federal aid programs, could be used to explain federal aid. Pogue and Sgontz⁶ showed that many of the same variables used to "explain" variations in state and local expenditures have a high degree of "explanatory" power if applied to variations in federal aid by state. Accordingly, Horowitz⁷ removed the entire argument from the realm of a single equation, ordinary least squares regression model, and argued that because of the simultaneous nature of the system, particularly those factors that determine federal aid, the best approach would be to use the techniques of two-stage least squares regression models. In 1968, Osman⁸ replied on both counts. He pointed out that in most cases, with the exception of welfare, federal aid programs are in fact closed-ended. He felt, a priori, that it might be argued that strong pressure exists for a state to use all the funds apportioned to it. If such pressure exists, the amount available to a state determines the amount of aid it receives. It was argued that, since the amount apportioned appears to be largely free of feedback, the amount of aid received will also be free of feedback. That is, it will be an independent variable. Available statistics bear out this hypothesis. Osman concluded that federal aid is determined by forces outside the state and may be used as an independent variable. Osman went on to argue, however, that the same situation may not hold for welfare payments. There is no ceiling on total welfare expenditures and the terms of the federal program come close to making it an open-ended grant program. However, federal participation is open-ended only with respect to the ability of the state to enroll new program recipients, not with respect to payments per recipient. A second point raised by Morss,⁹ that of "correlating changes in a variable with components in its variable," was also dealt with by Osman. He pointed out that subtracting aid from the total state and local expenditure variable simply reduces the coefficient on the aid variable by 1.0. Similarly, he

³ Roy W. Bahl and Robert J. Saunders, "Determinants of Changes in State and Local Government Expenditures," *National Tax Journal*, Vol. 18, March 1965, pp. 50-57.

⁴ Jack W. Osman, "The Dual Impact of Federal Aid on State and Local Government Expenditures," *National Tax Journal*, Vol. 19, December 1966, pp. 362-372.

⁵ Elliott R. Morss, "Some Thoughts on the Determinants of State and Local Expenditures," *National Tax Journal*, Vol. 19, March 1966, pp. 95-103.

⁶ Thomas F. Pogue and L. G. Sgontz, "The Effect of Grants-in-Aid on State-Local Spending," *National Tax Journal*, Vol. 21, June 1968, pp. 190-199.

⁷ Ann R. Horowitz, "A Simultaneous-Equation Approach to the Problem of Explaining Interstate Differences in State and Local Government Expenditures," *Southern Economic Journal*, Vol. 34, April 1968, pp. 459-476.

⁸ Jack W. Osman, "On the Use of Intergovernmental Aid as an Expenditure Determinant," *National Tax Journal*, Vol. 21, June 1968, pp. 437-447.

⁹ Op. cit.

found that regressing state and local expenditures less federal aid, on the federal aid variable, within a multiple regression model still resulted in federal aid being a statistically significant determinant of state and local expenditures.

Further work by O'Brien¹⁰ concluded that grants and expenditures were not simultaneously determined. O'Brien's dependent variable was "net of federal grants" and therefore represented "expenditures from own funds." He concluded that ordinary least squares, two-stage least squares, and generalized least squares methods provided consistent estimates. Because two-stage least squares estimates of the grants coefficients were not significantly lower than the ordinary least squares estimates, he concluded that grants and expenditures are not simultaneously determined and that grants are an exogenous variable in the determination of expenditures.

APPLICATION OF EARLIER MODELS TO THE AB AND APTD PROGRAMS

With respect to our study, it was hoped that variables found in other earlier studies to "explain" state expenditure patterns would be relevant to the problem of "explaining" the variations in expenditure patterns for AB and APTD.

Three of the more promising models from studies we have just reviewed were tested using 1970 data on AB and APTD.

Our principal measure of the level of state AB and APTD assistance, as indicated, will be state expenditures for financial assistance. In doing this we exclude counseling and other services offered by state public welfare agencies. The availability of data dictates this decision. Data on assistance are reported separately while data on services are lumped with state expenditures for administration and training. In addition, because of potential overlap in the eligible populations for AB and APTD, data from these programs are pooled and considered as one welfare program for the handicapped. By doing this, we hope to avoid the problem of an individual who, for example, would qualify for AB in one state, but APTD if he lived in another state.

All of the models reviewed earlier dealt with total public assistance expenditures per capita. That is, they considered public welfare to include the entire program of administration, service, training, and assistance expenditures for AB, APTD, Old Age Assistance (OAA), and Aid to Families with Dependent Children (AFDC). As a first step, we tested three models with a subset of the public welfare data—data on financial assistance payments for state AB and APTD programs.

The first of the state expenditure models was Fabricant's. The model he developed to explain per capita state expenditures contained three variables: per capita income, population density, and percent urban. Based on 1942 data, his model of per capita public welfare expenditures is as follows:

$$E = -1.99 + 0.0072 I + 0.1835 U - 0.0212 D$$

where E = per capita expenditures for public welfare

I = per capita income 1938-42

U = urbanization, the percentage of the population in communities of over 2,500 in 1940

D = population density per square mile.

¹⁰ Thomas O'Brien, "Grants-in-Aid: Some Further Answers," *National Tax Journal*, Vol. 24, No. 1, March 1971, pp. 65-77.

Using this structural form, but substituting data for 1970, we get a low R^2 , a coefficient of determination of 0.32, and none of the variables were statistically significant using a t-statistic test, indicating the model is unsatisfactory when applied to AB and APTD.

The low R^2 is consistent with the results reported by Sacks and Harris. They found that, as federal aid became a larger and larger part of the welfare program over time, this particular model increasingly failed to explain the level of state expenditures.¹¹ Sacks and Harris expanded the basic Fabricant model, adding federal aid to the states as a variable. Their model for per capita public welfare expenditures is as follows:

$$E = 17.70 + 1.07I - 0.023U + 0.003D + 1.683F$$

where E, I, U and D are as before and F is per capita federal aid to welfare. This structural form applied to 1970 AB and APTD data also gave unsatisfactory results comparable to those obtained with the Fabricant model. In an attempt to further refine these models, Osman and others added various socio-economic variables and selected population variables. The welfare function which Osman finally accepted contained only three variables—percent urbanization, percent of population over 65, and per capita federal aid to welfare. In equation form, this is as follows:

$$E = - 18.00123 + 0.21422U + 1.29032A + 1.37649F$$

where E, U and F are as before and A is the percent of population 65 years of age and over. Using this structural form and 1970 AB and APTD data, we again obtained unsatisfactory explanatory results.

These three models are representative of the ordinary least squares (OLS) approach to studying the determinants of state expenditures. From our standpoint, they appear to be of little use for several reasons. First, the low R^2 's and insignificant variables indicated by the t-test suggest that the models are not well-specified with respect to our problem. They provide no firm explanations of the variations in state expenditures for welfare to the handicapped. Second, from the standpoint of federal policy, they are of little help. The independent variables are, in general, factors beyond the control of federal policy. Third, OLS is not an appropriate tool when the problem is one of joint determination; it will yield unbiased estimates only when all explanatory variables are exogenous. Based on the formula for the federal proportion of state AB and APTD welfare payments, we feel that the problem is one of joint determination. In an OLS system there is no accounting for the interaction of the expected level of federal participation with the state decision of payment level and numbers served. This interactive process can be dealt with in a two-stage least squares regression model.

Little has been done, however, with two-stage least squares (TSLS) regression models. Horowitz and O'Brien published two studies attempting a simultaneous equation estimate of grants and expenditures. Horowitz used a TSLS approach to study interstate differences in state and local expenditures and employment. In her model, per capita expenditures, tax effort, income distribution, and federal grants were determined simultaneously. The principal findings were:

1. The higher the level of per capita personal income the higher are per capita state and local government expenditures.

¹¹ Using the same structural form as Fabricant, Sacks and Harris found using 1957 and 1960 data, R^2 's of .14 and .11, respectively.

2. There is a positive relationship between tax effort and the amount of public goods and services provided.
3. When the effects of federal aid are held constant there are neither economies nor diseconomies associated with per capita public expenditures.
4. For states with the same per capita income, tax effort, and distribution of income, state and local expenditures per capita will differ by \$1.26 for each difference of \$1 in per capita federal grants-in-aid.

O'Brien's study looked at whether grants and expenditures were determined simultaneously and whether federal funds stimulate or substitute for state and local expenditures. With his model he found that the OLS and TSLS estimates of the grants coefficients were not significantly different. From this result, specific to the model he used, he concluded that, in general, grants and expenditures are not simultaneously determined. We argue that while this could well be true for the closed-ended programs, the conclusion is inconsistent with the formula used in the open-ended programs. Taking a cue from Horowitz's work, we developed a model thought to be more appropriate to the questions of concern to us.

A SIMULTANEOUS EQUATION MODEL OF AB AND APTD EXPENDITURES

In our model, federal expenditures (FC), state expenditures (SC) and number of recipients (N) are the three endogenous variables that are determined simultaneously. SC is assumed to be a linear function of FC, N and state revenue (R). Federal cost is taken as a linear function of SC, N and per capita income (Y). These variables, by statute, determine the amount of federal aid to a state. N is assumed to depend on SC, Y and the state disabled population (D). Using this structural form and data from 48 states,¹² the estimated coefficients in the second stage are as follows:

$$\begin{aligned}
 FC &= -5686 - .4517 SC + .6934 N + 1.549 Y \\
 &\quad (-3.770) \quad (10.89) \quad (2.074) \\
 SC &= -561.9 - 1.681 FC + 0.8423 N + 4.535 R \\
 &\quad (-2.737) \quad (2.191) \quad (3.040) \\
 N &= 22,580 + 0.9738 SC + 0.045 D - 5.931 Y \\
 &\quad (6.558) \quad (6.674) \quad (-4.293)
 \end{aligned}$$

The reduced form equations are as follows:

$$\begin{aligned}
 FC &= 10,650 - 2.840 Y + 1.825 R + 0.0254 D \\
 &\quad (-2.676) \quad (2.073) \quad (3.416) \\
 SC &= 3055 - 1.236 Y + 8.163 R - 0.0262 D \\
 &\quad (-1.242) \quad (9.888) \quad (-3.764) \\
 N &= 25,550 - 7.135 Y + 7.950 R + 0.0195 D \\
 &\quad (-3.543) \quad (4.758) \quad (1.385)
 \end{aligned}$$

To talk about the interactive effects we look first at the results of the second stage equations. To discuss the net effects, we will then look at the reduced form equations.

¹² Nevada was excluded because it had no APTD program, and California was excluded as a statistical outlier that would significantly distort the coefficient estimates.

The variables in the federal cost equation are those in the formula used to determine the amount of federal reimbursement. For the first \$37 of the average grant, the federal government paid the states \$31. From \$38 to \$75, if the grant was that high, the federal government paid a varying portion depending on state per capita income. Beyond \$75 the total cost of the grant was born by the state. In 1970, state average grants for AB and APTD were all above the \$37 level, and most were above \$75. Therefore, for an increase in program assistance costs due to an increased average grant, federal cost would increase if the grant was in the range \$38 to \$75, but above \$75, federal cost would not change. If, however, program costs increased due to increased numbers of recipients, holding the average grant constant, federal cost would increase by the change in N times the federal share. We would expect, on the basis of the grant formula, that $\partial FC / \partial SC$ would be greater than zero. That it is less than zero suggests that as state average grants increased beyond \$75, this increase was related to higher per capita income. This higher per capita income in turn reduced the federal share and so would explain the result, which was that $\partial FC / \partial SC$ was less than zero.

The federal share of the amount of the assistance payment between \$38 and \$75 is a function of state per capita income. That is, as state per capita income increases relative to average state per capita income, the federal share is supposed to decrease. We would expect, therefore, that the change in federal cost due to a change in state per capita income, with SC and N held constant, to be less than zero. In our second stage, however, $\partial FC / \partial Y$ is positive. This could be due to the fact that the federal percentage is subject to two calculations. The first is related directly to per capita income and program expenses. This is known as the regular formula. The second, the alternate formula, while also a function of per capita income, allows states operating an approved plan for medical assistance (Title XIX) to use the "federal medical assistance percentage." If a state uses the regular formula, only the first \$75 of the average grant is eligible for reimbursement. The federal percentage is applied to the portion between \$38 and \$75. Maximum federal participation is \$75 times the number of recipients in the program. If a state uses the alternate formula, however, it is allowed to pool the assistance payments made for OAA, AB, APTD and AFDC and there is no maximum for the federal share to be paid on these assistance categories. (The maximum under the regular formula is 83 percent). In effect then, the basis of the state reimbursement formula can be raised by pooling the payments in the programs of interest to us with those for OAA and AFDC. The effect of per capita income on federal cost could be dominated by the total of the programs subject to the "federal medical assistance percentage." That is, as per capita income increases, we would expect the "federal medical assistance percentage" to decrease. But if this decrease is small, or if there is no change at all due to national increases in per capita income, it would be expected that if increased per capita income leads to a larger state welfare program in total, federal cost would increase in total and by type. One implication of this hypothesis is that the elasticity of federal cost with respect to per capita income will be less than one. We can test this implication by referring back to the reduced form equations. We find that in fact the elasticity of federal cost with respect to per capita income is less than one. In addition, if this hypothesis is true, we would expect the elasticity of state cost with respect to per capita income to be greater than the elasticity of federal cost with respect to income. For a typical state, e.g., Minnesota, where per capita income is about equal to the national average per capita income, the ratio of these two elasticities is less than one, supporting our hypothesis.

These two results, the opposite signs of both $\partial FC / \partial SC$ and $\partial FC / \partial Y$, suggest that the welfare program cannot be studied in isolation from the provisions of Title

XIX. A more complete specification of the interrelations of all assistance programs is required. This suggests, in addition, that before proposing changes in money assistance payments there must be an understanding of how federal and state payments will be affected by the various formulas used to compute federal reimbursement.

The remaining relationships in the equation system are as would be predicted. Given the open-ended program and the formulas for federal reimbursement, the signs of $\partial FC / \partial N$ and $\partial SC / \partial N$ are as expected. That is, as the number of recipients increases, and given an unchanged average payment level, we would expect an increase in program costs and hence an increase in both state and federal costs.

The sign of $\partial SC / \partial R$ is positive. This result is consistent with the expectation that "wealthier" states, those with larger revenues, would have larger assistance programs both in terms of numbers of recipients and average grants. Together, these factors lead to increased program cost and hence to both increased state and federal costs of supporting the program.

The positive sign on $\partial N / \partial SC$ implies that increased program expenditures go not only to increased payment levels but also to an increased number of recipients. Total program costs, and hence state cost, can increase either due to increased numbers of recipients or increased payment levels.

We would expect the number of recipients to vary directly with the eligible population. Thus the sign of $\partial N / \partial D$ is as expected. With respect to per capita income, using this aggregate measure, it would be expected, that as per capita income increased, average grant size would increase, and the number of recipients would decrease. That is, given the income requirements of a welfare program, as per capita income increases, fewer people meet the income requirements for AB and APTD.

Considering the two coefficients for N together suggests that the burden of the cost of an additional recipient falls more on the state than on the federal government. This would appear to be true at high payment levels. If the grant were \$150, for example, and the state used the regular formula with a federal percentage of 50 percent, an additional recipient would cost each government as follows:

Grant	State Share	Federal Share
\$0 — \$37	\$ 6	\$31
\$38 — \$75	19	19
\$75 — \$150	75	0
	\$100	\$50

In other words, the state would bear two-thirds of the cost, the federal government one-third. Such a burden could well be too great for the state and serve to discourage any outreach efforts.

The net effects, as shown by the reduced form equations, have already been discussed in terms of the relationships between federal cost, state cost, and per capita income. The positive sign on R in every equation of the reduced form supports our earlier statement that higher state revenues lead to larger programs, both in terms of payments and recipients and hence to increased state and federal costs. The one anomaly in the system is the negative sign on D (state disabled population) in the state cost equation. While its contribution is small, the coefficient is significant.

The difference of our results in some cases from what would have been predicted a priori suggests immediately that the system is not as simple as it has been specified in the model. More important, the influence of the reimbursement formulas is apparent but not captured completely in the model. In addition, because the welfare alternate formula is tied to other than welfare payments we cannot look at welfare

alone; state reimbursement for this activity is tied to state payments for medical assistance, for example.

Finally, unlike other determinants models, this is not a per capita model. We tested a closely related simultaneous equation per capita model, but none of the variables had high statistical significance. Hence, we feel that more research is required to develop better models, and to supplement currently available data to make it feasible to use those better models. Consequently, we draw no policy conclusions from the analyses in this appendix.

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