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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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

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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.

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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

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, preschool 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 officials 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.