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

This is an abridgment of Rand report R-1220-HEW, Services for Handicapped Youth: A Program Overview, which is the first of two reports describing a comprehensive, 22-month cross-agency evaluation of Federal and state programs for assistance to handicapped youth. The Rand Corporation is performing the study during the period February 1972 through December 1973 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 (DHEW).

DHEW officials defined two broad purposes that are reflected in the study. 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 of the present service system. The second is to assist DHEW officials in improving the system by evaluating current policies and providing information on alternative future policies to improve the delivery of services to youth with hearing or vision handicaps. The results of this study are intended for use by the Assistant Secretary and other Federal officials, by state agencies, by associations representing the handicapped, as well as by the general public.

This abridgment is being issued for the convenience of persons who might be interested in the findings but not the details of the study.
SUMMARY

This is an abridgment of the first of two reports on the findings of The Rand Corporation's cross-agency evaluation of government programs for the more than 9 million mentally or physically handicapped youth aged 0-21 who are impaired enough to need services not required by "normal" youth. Handicapped individuals included are those generally called visually or auditorily impaired, speech impaired, crippled or other health impaired, mentally retarded, emotionally disturbed, or learning disabled. Excluded are those whose problems tend to be more attributable to conditions in society rather than to a physical or mental disability, e.g., the "disadvantaged" youth.

For ease of presentation, we grouped the programs into areas by the five different types of agencies that administer them: health, welfare, education, vocational rehabilitation, and mental health and retardation. These programs offer a wide variety of services: activities intended to prevent the occurrence of handicapping conditions, the identification of the handicap, direction to the appropriate service providers, counseling, medical treatment, education, special training (e.g., in mobility or speech), vocational training, job placement, the creation and provision of sensory aids or other equipment, recreation and social activity, personal care, income maintenance, training of personnel to supply the services, construction of service facilities, and research and development.

In recent years all such programs expended nearly $5 billion annually for services. This report provides a descriptive overview of the population of handicapped youth, the structure and functioning of the system, the current state and Federal service programs, the resources devoted to various classes of handicapped youth, and the services delivered. Also identified are major problems of the present service system, both in the services delivered and in the institutional structure of some of the programs.

Over 50 major Federal programs help provide services to handicapped youth. Federal, state, and local government service programs and expenditures have expanded considerably in recent years and have very beneficial effects; but, taken together as a system, these programs and services have some major problems: inequities, gaps in service, insufficient knowledge, inadequate or deficient control, and insufficiency of resources.

A subsequent report, focused on youth with hearing or vision handicaps, will
use this and other information in analyzing alternative means of improving the service system.

The full unabridged version of this report, R-1220-HEW, provides detailed information on programs, services, problems, and next steps in the research.
ACKNOWLEDGMENTS

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

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

Several dozen families with handicapped children, several organizations representing the handicapped, and several 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. L. M. Wallen is responsible for study inputs based on the survey of families with handicapped youth described in Appendix E. S. A. Haggart, G. R. Hall, C. N. Johnson, K. Kellen, H. L. Moshin, L. L. Prusoff, M. L. Rapp, and E. Woodward 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 manuscript preparation. P. Y. Hammond and E. S. Quade reviewed and made helpful comments concerning earlier drafts of this report. We are grateful for their assistance.
"A CRISIS OF CONTROL"

There is, in my opinion, a developing crisis—still largely hidden—facing the human service sector of our society, a crisis which may challenge the fundamental capability of our society to govern itself.

It is a crisis of performance—our institutions are failing to live up to our expectations.

It is a crisis of control—in many fundamental respects the human service system is developing beyond the scope of Executive control... or of Congressional control... or of consumer control... or of public control.

—Elliott L. Richardson, "Responsibility and Responsiveness (II),"
INTRODUCTION

This is an abridged version of the first 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.

Handicapped youth, as defined here, include those 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. This includes people who are generally called visually or auditorily impaired, speech impaired, crippled or other health impaired, mentally retarded, emotionally disturbed, or learning disabled. Excluded are those whose problems are more attributable to conditions in society than to a physical or mental disability, e.g., the “disadvantaged” youth.

Estimates of the number of handicapped youth vary widely depending on the definitions used, the data believed, and the type of service needed. Definitions of handicaps are not consistent among service agencies. The handicap, if defined at all, is almost never clearly stated and, hence, reliable data on the prevalence of handicapping conditions in youth generally are not available.

The proportions of the problem are clearly indicated if one considers that of the 83.8 million youth aged 0 to 21 in the United States in 1970, more than 9 million were handicapped. While we are not fully satisfied with the reliability of the estimates presented in Table 1, we believe that they do represent the correct order of magnitude regarding individuals who require at least some special services. Appendix A of the unabridged report discusses these and other estimates and definitions.

Scope of the Research

The first report focuses on existing Federal and state programs providing services to all types of mentally or physically handicapped youth, giving a descriptive

<table>
<thead>
<tr>
<th>Type of Handicap</th>
<th>Number of Youth</th>
</tr>
</thead>
<tbody>
<tr>
<td>Visual impairment</td>
<td>193,000</td>
</tr>
<tr>
<td>Partially sighted</td>
<td>180,000</td>
</tr>
<tr>
<td>Legally blind</td>
<td>45,000</td>
</tr>
<tr>
<td>Hearing impairment</td>
<td>2,200,000</td>
</tr>
<tr>
<td>Hard of hearing</td>
<td>440,000</td>
</tr>
<tr>
<td>Deaf</td>
<td>50,000</td>
</tr>
<tr>
<td>Speech impairment</td>
<td>1,676,000</td>
</tr>
<tr>
<td>Crippling or other health impairment</td>
<td>1,500,000</td>
</tr>
<tr>
<td>Mental retardation</td>
<td>2,800,000</td>
</tr>
<tr>
<td>Emotional disturbance</td>
<td>740,000</td>
</tr>
<tr>
<td>Learning disability</td>
<td>1,500,000</td>
</tr>
<tr>
<td>Multihandicapped</td>
<td>50,000</td>
</tr>
<tr>
<td>Total</td>
<td>9,550,000</td>
</tr>
</tbody>
</table>

a Including 32,000 partially sighted.
overview of those programs and many of their problems and covering the following subject matter:

- The handicapped youth population.
- The services considered include the following: prevention of the handicapping condition, identification of the handicap, 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 comprising the current service system being evaluated are all those through which Federal and state governments contribute to the provision of the above services to handicapped youth.
- The information to be provided, within the limitations of available data, includes the institutional structure, functional service delivery mechanisms, clientele, resources devoted to various classes of handicapped youth, and related problems.

The second report on alternative future Federal policies to improve the delivery of services to handicapped youth provides the following information:

- The target population will be limited to auditorially and/or visually handicapped youth.¹
- The services considered will remain the same as above, but the system will be expanded to include local and private programs, as well as those of the Federal and state governments.
- The alternative future policies to be analyzed are those that the Federal Government might adopt to help alleviate problems, to improve the services delivered to sensorially handicapped youth, and to improve the institutional structure and functioning of the service system.

The scope of this entire research project is necessarily large and comprehensive, because the programs and problems of serving handicapped youth are also large and comprehensive. Insufficient evaluation data necessarily limit the degree to which definitive analyses and recommendations can be presented. Because this is an overview study using available data, it cannot answer all questions, but it does generate a good deal of new information and perspective.

Research Approach

We have chosen a research approach that is comprehensive, policy-oriented, problem-centered, and interdisciplinary, and in doing so certain strengths and limitations of the effort naturally follow.

¹ Auditorially and visually handicapped youth were singled out at HEW’s request because their 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 has been developed to serve them; the data appear more readily available for these handicaps than for some others; and the assessment of program objectives, effectiveness, and benefits may be more easily assessed than those for other handicapping conditions such as emotional disturbance.
In being *comprehensive*, we view the whole system serving handicapped children and youth and are able to better assess the interrelationships of the system's constituent parts to its whole. Such a view is not commonly taken by any identifiable government unit, and this is basically why Rand was asked to undertake this research. Because of the conscious choice to be comprehensive, we may very well err in reporting or failing to report some important details about the nature and operations of the individual parts of the system. We are aware of the problem and have worked diligently to minimize it.

In being *policy-oriented*, we identify three basic client groups for this work: various governmental agencies, the populations served, and the public in general. These groups are mirrored in our concern, respectively, with the whole system view and the relationships of its various parts to the whole; with detail on the individual level obtained through interviews and a family survey; and with the general public through the structuring of the analytic questions in our subsequent report—especially as they concern economic efficiency criteria. A policy orientation does present problems. Almost invariably a policymaker works with sparse information, and existing data almost never exactly answer his specific questions. Data are in inappropriate formats, are unavailable, are unreliable, are not easily analyzed with conventional data processing techniques, and so forth. We explicitly discuss the problems created by data deficiencies, however; e.g., assumptions, limitations, and the extent of data quality and reliability are spelled out—and we treat these problems as carefully as possible.

In being *problem-centered*, we try to identify the actual operational problems in a given system context, both those reported by system participants and those which individuals—because of parochial interests, limited perspectives, or both—are unaware of. We have responded to the former demand by interviewing, surveying, and otherwise attempting to elicit individual points of view, and we have responded to the latter demand by viewing the system according to its programs, services, and participants at levels of resolution ranging from the grossest to the most detailed. In doing so, we have identified problems not commonly known or widely appreciated, as well as those that are.

The problem-centered approach is beyond the skill and endurance of any one individual and calls for *interdisciplinary* research: the work must be done by a team having a variety of talents and interests. Our group includes individuals trained in operations research, public administration, political science, business administration, economics, and applied mathematics. Consultative specialists, physicians primarily, have been called upon whenever needed.

Evaluations have often been criticized as mere excuses to maintain the status quo; they have resulted in little or no constructive change, and their existence has often proved to be more mildly diversionary than substantial. We have no particular stake in the status quo, and our general attitude has been to describe events as well as possible and then "let the chips fall where they may." Subsequent detailed policy analyses are designed to evaluate system performance and effectiveness using a set of multiple criteria for measuring policy outcomes. Defined in terms of the goals of various different service system participants, these criteria include measures of current resource consumption, equity, future economic effects, and effects on the quality of life of the handicapped individual.
These basic types of criteria will be utilized to assess the implications of alternative policies on the service system, the handicapped population, and the public in general. None of these types of criteria is readily identifiable as the exclusive domain of a particular interest group, but all reflect real, general concerns about the current capability and future prospects of the system serving handicapped youth.

The research approach and evaluation framework we have adopted are generally useful to analyze programs for many different populations, not just those for sensorially handicapped youth.

Information Sources

To provide 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 (correctly, as it turned out) that information about the system would also be fragmented and that great effort would be required to collect and synthesize the data into a coherent picture.

We collected information from five different, basic sources: a survey questionnaire mailed to several major service agencies in each state; interviews with officials in 60 different Federal and state agencies; Federal and state reports and unpublished data on specific programs; existing literature in the field; and an interview survey of handicapped service recipients.

Structure of the Report

In the remainder of the report, we first describe our approach to the service system as seen in terms of models, functional mechanisms, rationales, policy processes, and objectives. Next, we examine the service programs by the five types of agencies that administer them: health, welfare, education, vocational rehabilitation, and mental health and retardation. Then we discuss the individual services the system provides, and finally we consider the problems of the present service system.

MAPPING THE SERVICE SYSTEM

The assortment of institutions providing services to this 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 this system, we have devised an intellectual "map" to help locate and describe various aspects of the service system. First, we define coarse-grained, low-resolution models of the operational institutions and the respective roles they perform. Next, we describe functional mechanisms by which those key institutions produce services. Then, rationales, both implicit and explicit, being advanced to justify the selection of broad classes of functional activities constituting policies and programs, are postulated to provide a sense of why the system functions as it does. Key policy processes by which the system appears to operate and change are laid out by detailing a general se-
quence of events through which policies and programs are created, implemented, and eventually ended. And, finally, objectives toward which the system strives are considered.

This map, while not precise, gives an overview of the service system, and that has rarely been done in the past. In our next report, these models, functional mechanisms, rationales, and policy processes should prove useful in conceptualizing and analyzing alternative future Federal roles in providing various services to handicapped youth.

Models of Federal Institutional Roles

At least four separate institutional roles for the Federal Government are discernible in programs, and while we would not claim that a given operating institution conforms exactly to any one of these models, describing the pure model types helps to locate specific governmental institutions within the context of the larger system.

There are essentially four dimensions along which one may define the basic models: operations, policy and program control, dollars, and innovation/stimulation. Each dimension is a measure indicating a different degree and type of responsibility and authority vested in and exercised by any given institution. The dimensions may be illustrated by posing the following operational questions:

- **Operations:** Is the institution directly providing services? Is it the delivery point for the affected population?
- **Policy and Program Control:** Is the institution mainly responsible for developing and monitoring policies and programs designed to produce specified services?
- **Dollars:** Is the institution the primary source of funds supporting a given service or collection of services? Does it have the power to change the amount of those funds?
- **Innovation/Stimulation:** Is the institution responsible primarily for creating new ideas, programs, and policies and for encouraging operational agencies to adopt practices and procedures reflective of these ideas? Research, development, demonstrations, and so-called “social experiments” are illustrative activities.

The four basic models we characterize are really points on a continuum of different roles the service institutions may play.

**Model I: "Direct Operation":** If a single institution (or collection of institutions all related to the same service area) is the primary locus for direct service delivery, policy and program control, dollar support, and new developments, then that one institution or cluster of related institutions is playing a comprehensive role which we term "Direct Operation," since it is the direct service delivery that distinguishes this model from the following models.

**Model II: "Controllership":** In the "Controllership" model, operation (direct service provision) is reduced or nonexistent. This model is the same as the Direct Operation model except that the actual services are delivered (according to carefully prescribed guidelines and subject to authoritative evaluation) by subordinate agents such as the states and localities.
Model III: "Special Revenue Sharing, Plus": We use the term "special revenue sharing" in its de facto not its de jure sense. While initiatives to introduce special revenue sharing for education, health, and social services are all awaiting formal adoption, in facta number of existing, identifiable programs already have characteristics that could best be described as special revenue sharing. This model type provides funds, and may support innovation or research, but very little concern is evidenced for program control or direct service provision. The "Plus" represents the concept that the Federal Government has some right and obligation to evaluate the performance of agencies receiving special revenue sharing funds, yet may also engage in innovation related activities.

Model IV: "Catalytic": Research, development, demonstration, social experiments, and seed funding are all characteristics of the "Catalytic" model, whereas direct service provision, service funding, and service policy control are not.

Functional Mechanisms

The "model type" concept refers to some basic ideas about the functional mechanisms used to produce certain fundamental services: the system's "products" as seen primarily from the perspective of the "consumer"—the handicapped child and his family. The general functional mechanisms that Federal institutions use to help produce a range of definable services or products include (1) providing services directly, (2) purchasing services through state or local government institutions, (3) regulating those providing services, (4) investing in manpower and facilities that eventually contribute to an adequate supply of services, and (5) searching for and disseminating information about the system, its problems, its participants, and improved ways to provide services.

Rationales

The underlying reasons used to explain and justify the creation and existence of both the functional mechanisms of programs and the services they produce vary greatly in number, degree of ambiguity, and means of articulation. These rationales and their characteristic arguments may be grouped into five general types: (1) resource redistribution to increase productivity, increase equity, or to fill unmet needs; (2) economies of scale; (3) internalization of externalities; (4) control and responsiveness; and (5) stimulation.

As rationales are arguments or appeals to marshal support or to justify actions, they take on numerous, seldom unambiguous, and often contradictory forms. They are nevertheless important, commonly used, and must be considered if we are to fully comprehend the complex handicapped youth service system.

The Policy Process

A final way of visualizing the service programs considers a sequence of events through which its policies and programs flow from initiation through termination. This sequence includes the following distinct, but interrelated phases: (1) initiation and invention—sensing and creating a wide range of plausible means to alleviate,
mitigate, or resolve some perceived problem or demand for action; (2) estimation—narrowing the initial list of plausible alternatives according to some rational scientific and normative criteria; (3) selection—the political and bureaucratic decision processes for choosing one from a set of plausible, feasible, and acceptable options that have been invented and estimated; (4) implementation—executing the selected option according to some plan; (5) evaluation—determining responsibility for the calculated outcomes of the policy, taking into account individual and institutional performance and feedbacks to subsequent phases of the sequence; and (6) termination—eliminating or adjusting policies that have become dysfunctional, redundant, unnecessary, or outmoded.

This is a dynamic process through which any policy or program passes—in effect the “life cycle of policies.” Such a perspective is helpful in understanding the timing, participants, and demands placed on the system at each stage, as well as in understanding (1) why a given specific program or a general policy has evolved, (2) where a program is currently located in the process (and hence where it is likely to go), and (3) how the overall system works toward improving that operation.

Objectives

Understanding a system’s diverse goals or objectives is one key to improving performance. It is essential to isolate and specify the stated and unstated objectives of all key participants in the decision sequence just outlined, of participants involved in operating the system, and the goals of the service recipients. For instance, the objectives posited by a legislator have characteristic influences in formulation and implementation of policy for handicapped youth, while objectives of the parents of an individual child may be quite different. Each participant’s objectives must be understood to determine the extent and impacts of these differences. Whose goals are being furthered by the system’s performance and operation, and whose are not?

THE PROGRAM VIEWPOINT

The unabridged version of this report describes over 50 different major identifiable Federal 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. Despite the length of the full report, many programs are not discussed because they involve low expenditures, affect very few handicapped youth, or deliver the same volume and type of service whether or not the child is handicapped. The selection of the proper set of programs to include depends upon the policy decision addressed. Since this study does not focus on a single policy question, we include programs that are now, or seem likely to be, strongly relevant to policy alternatives for assisting handicapped youth. For ease of presentation, we grouped the programs into areas

---

1 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).
by the five different types of agencies that administer them: health, welfare, education, vocational rehabilitation, and mental health and retardation.

Figures 1 and 2 show, by type of agency, breakdowns of the estimated total annual government expenditures of $4.7 billion for services to handicapped youth. Amounts shown are all for a single fiscal year, 1970, 1971, or 1972, depending on the data available. Note that special education agency programs alone account for over half of the expenditures, followed by mental health and retardation and welfare agency programs. The Federal expenditures of an estimated $1.1 billion annually represent only about $1 from Federal sources for every $3 from non-Federal sources; however, Federal financial involvement in each program area varies considerably. The largest program area for Federal funds is special education, followed by welfare and health. Also note that non-Federal funding predominates in education, and mental health and mental retardation, whereas Federal funding predominates for health and vocational services. Welfare is about evenly divided between Federal and non-Federal funding.

Fig. 1—Government expenditures for handicapped youth
Figure 2—Percentage of government expenditures for handicapped youth by type of agency.

Figure 3 shows the distribution of funds among handicapping conditions. The mentally retarded are receiving over $2 billion annually, which is by far the largest share (43 percent) going to any handicapped group. Much of this money is spent on special education ($1.2 billion) and residential institutions ($0.5 billion). The emotionally disturbed receive the next largest share with 17 percent of all expenditures. The other handicaps (vision, hearing, speech impairments, crippling and other health impairments, and learning disabilities) each receive less than 13 percent of the total.

Total budgets, however, do not give much insight into the services flowing to each handicapped person. One way of examining per capita costs is to look at the
average annual cost per handicapped youth in the United States. As estimated earlier, this population is approximately 9.55 million, and hence the average annual government expenditure per handicapped youth is $495. This does not mean that each person receives $495 worth of government service annually. Some obviously receive much more and many receive nothing. Figure 4 shows the distribution of this average cost among service agencies by type of handicap.

Note that the expenditures per visually handicapped youth, at $793 annually, are higher than for any other handicap, and are followed closely by the expenditures per mentally retarded youth, at $726 annually. Expenditures per speech impaired youth are lowest, at $247 annually. On a per capita basis, no one type of handicap dominates expenditures, as the mentally retarded appear to do if one considers only the total expenditures without considering the relative size of the various segments.
of the handicapped population. Also note that the expenditures in Fig. 4 are per handicapped youth, not per handicapped youth served. Funds expended per handicapped youth served are considerably higher, as described below.

**Special Education**

Of the $2.679 billion spent annually on special educational services for handicapped youth, 88 percent is non-Federal funding and the bulk is spent in support of special education classes in the regular schools and in residential schools for the more severely impaired. An estimated 3,046,000 handicapped youth were assisted in 1971, or about 7 percent of the public school enrollment. Thus, annual expendi-
tures per youth served averaged $879, but varied from $188 for a speech-impaired youth up to $2900 for a deaf youngster. The three major types of Federal programs were

1. Programs for instructing students (78 percent of Federal special education expenditures), such as the Education of the Handicapped Act (EHA), part B; Elementary and Secondary Education Act (ESEA), Titles I and III; Head Start; the Vocational Education Act; the Higher Education Act; the federally funded schools for the deaf (Gallaudet College, the National Technical Institute for the Deaf, Kendall, and the Model Secondary Schools); and programs targeted at the deaf-blind, early education, and youth with learning disabilities.

2. Programs designed to produce teachers and instructional materials (18 percent of Federal expenditures) such as EHA, parts C, D, and F; the Education Professions Development program; the American Printing House for the Blind; and the Library of Congress program.

3. Programs sponsoring research (4 percent of Federal expenditures) such as EHA, part E.

When a program also serves clientele who are not mentally or physically handicapped youth, then only the relevant portion of its budget is included in our totals. Almost half of the Federal funds went toward stimulating and diffusing services in the states via the functional mechanisms of services purchased through state and local agencies, and of investments made in ways of providing services. The U.S. Bureau of Education for the Handicapped (BHEH) manages only about half of the Federal special education funds we identified. The courts in some states are also becoming more active via mandates concerning the "right to education" for the handicapped. The Federal role vis-a-vis the states is not a dominant one, but appears to be a hybrid and changing one that is at present primarily our Catalytic model.

Mental Health and Retardation

This program area ranks second with $898 million or 17 percent of the total expenditures. The Federal share of the total is about 8 percent. This excludes amounts for the mentally handicapped that are not channeled through mental health and retardation agencies, since those expenditures are included in the totals for those other program areas. The total expenditures for all government agencies on mentally handicapped youth are estimated to be $2.8 billion annually. A breakdown of the funds channeled through mental health and retardation agencies indicates that more than half is spent on residential care of the mentally retarded, even though only 1 in 25 of the retarded youth receive this type of care. Residential care for the mentally ill accounts for another 30 percent. Approximately a quarter million mentally handicapped youth were treated as inpatients in 1970, at an average cost of approximately $2960. Funds are also spent on outpatient care, and the expenditures for 570,000 mentally ill young persons who were treated as outpatients averaged about $150. Of Federal programs, the two largest were the Developmental Disabilities program, primarily serving retarded persons, and the National Institute of Mental Health's Community Mental Health Center program. Federal programs also include research, training, hospital improvements, grants, and the operation of
St. Elizabeths Hospital. Another significant Federal activity is that of the President’s and Secretary’s Committees on Mental Retardation. Literally all of our characteristic role models exist in some Federal mental health or retardation program, but none is developed sufficiently well that it predominates.

**Welfare**

The third largest category of program expenditures for the handicapped is welfare—13.4 percent of total expenditures, or $635 million. The total Federal, state, and local shares were 54.6, 34.6, and 10.8 percent, respectively. The five primary programs serving about one million youth annually are Social Security Disability Insurance (SSDI); Supplemental Security Income (SSI) providing aid to the aged, blind, and disabled; Aid to Families with Dependent Children (AFDC); General Assistance (GA); and Income Tax Exemption for the Blind (ITEB). The average yearly expenditure per youth served is about $635. Most of this assistance is provided through AFDC because the family is poor and not because a child is handicapped (although having a handicapped child could be a factor contributing to that poverty). The Federal Government uses two primary functional mechanisms in this program area: Direct provision of services in the SSDI and SSI programs, and purchase of services through state and local agencies in the large AFDC program. As the Federal Government expands its welfare role, it is clearly trending toward our Direct Operation model.

**Health**

Physical health services consume $315 million or 6.7 percent of the total amount expended by governments on handicapped youth. The Federal Government provides 65 percent of that total. Most of this money pays for health care for about one million poor and medically needy handicapped youth under the Medicaid program, at an average annual per capita cost of approximately $250. The federally supported Crippled Children’s Service served 485,000 medically indigent youth in 1971 at an average per capita cost of about $180. Note then that while these two major health programs serve handicapped youth, they are distinctly oriented toward the poor. Other federally supported programs were for research (the National Institutes of Health primarily), for prevention (e.g., the rubella immunization program), and for other services (e.g., the Maternal and Child Health Care clinics, and the vision and hearing screening program). In addition to HEW, we found health care programs for handicapped youth in agencies such as the Veterans Administration and the Department of Defense.

The Medicaid program is an example of our Controllership model; the Maternal and Child Health program is best described as our Special Revenue Sharing, Plus model, but without the Plus; the Crippled Children’s Service program is also a form of Special Revenue Sharing, but the evaluative and quality control Plus is moderately well developed; and the general National Institutes of Health program of research, demonstration, and dissemination of information is an example of the Catalytic role model.
Vocational Services

The smallest component of total expenditures (4.3 percent) is for vocational services, with an annual cost of $202 million. The Vocational Rehabilitation program provided a comprehensive set of services through state agencies for 101,000 handicapped youth whose cases were closed in 1970 for about $1300 apiece. Seventy-seven percent of the young clients accepted for service were rehabilitated. Another major federally supported program is the State Employment Service, which spent an estimated total of $3,750,000 on handicapped youth in 1972. The Presidential Committee on Employment of the Handicapped and the affiliated state and local committees also work to promote employment of the handicapped. Relatively few funds are expended on service personnel training and facilities construction. The Federal role in vocational service expenditures is most nearly our Controllership model.

THE SERVICE VIEWPOINT

To this point we have focused on individual agencies serving handicapped youth. Focusing solely on agency activity, however, does not yield a complete picture of the overall service system. Viewed from the perspective of services rather than agencies, we see a rich mosaic of the following features: (1) prevention, (2) identification, (3) direction, (4) counseling, (5) medical treatment, (6) education, (7) special training, (8) vocational training, (9) job placement, (10) sensory aids/other equipment, (11) personal care, (12) recreation/social activity, (13) income maintenance and, indirectly, (14) service personnel training, (15) facilities construction, and (16) research. Our research indicates that the extent and efficacy of this system vary among specific handicaps, and discussions of these variances occur throughout the full report. Our present purpose is to lay out the entire system generally with respect to the different services. Describing the system in terms of the needs of the handicapped helps pinpoint gaps in service coverage.

Service types comprising the major and minor components of Federal and state agency programs for handicapped youth are shown in Table 2. While specialization is evident, all agencies to some degree provide a wide spectrum of services. Often, providing these services is not a formal, organized part of an agency's program, but occurs naturally or out of necessity, as with the case of counseling.

Nine of the enumerated services are not the major responsibility of any one agency. Presuming that these services are important in the lives of handicapped people, this lack of direct responsibility may make getting one of those services (e.g., a sensory aid) a difficult undertaking. Such "unassigned" services also appear to be generally underdeveloped and undersupplied.

Observing and concluding from Table 2 that major responsibilities are unduplicated across agencies is misleading because there are overlaps and some duplication of responsibility among different programs within the same generic type of agency.

To understand the services better, let us review each briefly.
Table 2
SERVICE COMPONENTS OF FEDERAL AND STATE AGENCY PROGRAMS
FOR HANDICAPPED YOUTH

<table>
<thead>
<tr>
<th>Type of Service</th>
<th>Type of Federal and State Agency</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Health</td>
</tr>
<tr>
<td>Prevention</td>
<td>m</td>
</tr>
<tr>
<td>Identification</td>
<td>-</td>
</tr>
<tr>
<td>Direction</td>
<td>-</td>
</tr>
<tr>
<td>Counseling/psychiatric care</td>
<td>m</td>
</tr>
<tr>
<td>Medical/surgical treatment</td>
<td>M</td>
</tr>
<tr>
<td>Education</td>
<td>-</td>
</tr>
<tr>
<td>Special training</td>
<td>-</td>
</tr>
<tr>
<td>Vocational training</td>
<td>-</td>
</tr>
<tr>
<td>Job placement</td>
<td>-</td>
</tr>
<tr>
<td>Sensory aids/other equipment</td>
<td>m</td>
</tr>
<tr>
<td>Recreation/social activity</td>
<td>-</td>
</tr>
<tr>
<td>Personal care</td>
<td>m</td>
</tr>
<tr>
<td>Income maintenance</td>
<td>-</td>
</tr>
<tr>
<td>Personnel training</td>
<td>m</td>
</tr>
<tr>
<td>Construction of facilities</td>
<td>m</td>
</tr>
<tr>
<td>Research</td>
<td>m</td>
</tr>
</tbody>
</table>

NOTE: M equals major component; m equals minor component; - equals little involvement.

Prevention

Specific precautionary measures are effective in preventing certain handicapping conditions. Rubella and other immunizations are excellent cases in point. Prevention, however, is a neglected service that no one agency has major responsibility for and that no one adequately provides. The few prevention programs that exist provide, at best, spotty coverage of the population. Of the $4.7 billion all governments spent annually on handicapped youth, we found less than $50 million targeted specifically for prevention activities.

Identification/Outreach

Three points were made repeatedly in our interviews with agencies and in our investigations of data related to handicapped services: (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 agency outreach programs exist to identify the population in need.

Identification is one of the more neglected services. The prime examples of existing formal identification programs, vision and hearing screening of children, are far from being universally offered and are virtually nonexistent for preschoolers (early detection is very important in some cases; e.g., the deaf who need early language development assistance). Most identification that does exist is informal, e.g., by schoolteachers or others not specially trained to recognize handicaps.
As important as the service is, particularly early identification, why is it so underdeveloped? One explanation is that all available service resources are being used already, so why go looking for more people? That may be answered in at least three ways: an equity-related answer is that those with the most need or the greatest ability to benefit are not all 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 nongovernmental supported services.

Erroneous identification is also a problem. Cases in point include labeling children as retarded when in fact lack of fluency in English or an auditory handicap is the actual problem.

Direction

This is a critically important but neglected service. The handicapped youth has complex needs, but there is a bewildering maze of agencies, services, and programs, many whose existence he is not even aware of. By direction, we mean the periodic and systematic matching of a youth’s needs with the proper mix of services to serve those needs. Individual needs change, for instance, as one ages or improves in response to services; the system’s capacity to serve is dynamic too. Direction is an information-based service designed to match individual needs and localized system capabilities as each changes.

In practice, direction has been no one’s prime responsibility and hence has become a major gap in the service package offered. Follow-up and redirection, activities implied in the idea of “periodic and systematic” service provision, are particularly underdeveloped. No one really provides this essential service except for isolated service personnel, dedicated individual pediatricians, teachers, social workers, or counselors, who must make extraordinary efforts to understand other aspects of the system to better advise about services which are not their specialties. Since comprehensive information about the system is not generally available, the quality of any direction service offered will be limited. Our next report will examine the possibility of creating a formal, localized, and comprehensive needs-evaluation and referral program.

Counseling

Professionals in each type of service agency undoubtedly do some counseling of the handicapped youth and his family regarding personal or psychological problems; e.g., counseling on understanding and adapting to the handicap, on interacting with others in society, or on occupational objectives. With the exception of psychiatric care, this service is provided in conjunction with and as a supplement to other services. Given the state of existing data and general information about the overall system, it is impossible to know how much counseling is provided and what its effects are.
Medical Treatment

Most of the $315 million that health agencies spent in FY 1971 was for treatment and, to a lesser extent, for training personnel and for research. Funds for medical treatment are also a minor component of other agency budgets; e.g., vocational rehabilitation pays for medical care if it advances the program's occupational goal. Over one million handicapped youth from needy families receive this service under provisions of Medicaid, while nearly one-half million youth from medically indigent families benefit under the Crippled Children's Service program. Thus, the health service programs may be characterized as being directed predominantly toward the low-income handicapped.

Education

More than half of the total government expenditures for handicapped youth go toward education, nearly $2.7 billion in 1971 (mostly non-Federal) for assistance to over 3,000,000 youth. The trend in service has been from serving a few, mainly in residential schools, toward serving many with a system providing a variety of kinds of special education: special day classes, itinerant special education teachers, and resource rooms to supplement the services provided in a normal classroom. The trend to serve more youth has been spurred by court decisions guaranteeing a "right to education" for all the handicapped. Yet, using BEH estimated incidence rates of handicapping conditions, and assuming all handicapped youth aged 5 to 17 need some special education service, we estimate that only 59 percent are served. Other assumptions lead to estimates as low as 36 percent served. There is extreme variation across the states, with the percent served varying from less than 20 to more than 90 percent (using the same assumptions to estimate the percentages for each state). While special education currently captures much legislative interest, the cost of providing different kinds of special education is not accurately known, and data on differences in effectiveness of each type are practically nonexistent.

Education agencies expect great versatility from teachers, since they also provide limited amounts of other services, such as screening for handicaps, counseling, training for mobility, activities of daily living, vocational training, and sensory aids.

Special Training

Availability of specialized training varies considerably according to the kind needed. If a handicapped youth needs speech therapy, he can generally receive it from schools. Other types of training needs, such as for mobility or for activities of daily living, are not the major responsibility of any single agency and are not widely available in public programs. Reliable data on the exact extent and amount of expenditures for these kinds of training are not available. Many kinds of special training are relatively inexpensive and, if provided, may significantly affect the handicapped youth's life style.
Vocational Training

Physically and mentally handicapped youth may have a restricted choice of occupations because of their impairment, but also may be vocationally impaired because of discrimination or lack of understanding on the part of potential employers. To counter these vocational handicaps, two programs primarily provide training service: Vocational Education (VE), which served 209,000 handicapped youth in 1970; and Vocational Rehabilitation (VR), which provided more extensive training to about 71,000 of its young clients. While data are not available on the success of the VE program, the VR program successfully rehabilitated 77 percent of its young clients. But there was great variation across states in the number of successfully treated young VR clients per 100,000 of the population aged 14-21. For example, in 1970, the range was from less than 100 to more than 500 per 100,000.

Job Placement

Two primary agencies help the handicapped locate employment—Vocational Rehabilitation and State Employment Services—but the latter offers a much less intensive placement service than does the former. Through activities designed to spread knowledge of the abilities of the handicapped generally to the public and potential employers, the Presidential Committee on Employment of the Handicapped and the corresponding committees in the states and localities promote employment opportunities for the handicapped. In total, about $10 to $15 million in government funds is spent annually for job placement of handicapped youth.

Prosthetics, Orthotics, Sensory Aids, and Other Equipment

The provision of equipment to the handicapped comprises this service. Primary examples of such equipment include closed-circuit television for the partially sighted, braces, artificial limbs, hearing aids, guide dogs, and canes. About one million people of all ages were using hearing aids, and a quarter of a million blind persons were using canes in 1970. The National Academy of Sciences Committee on Prosthetics Research and Development estimated that in 1970, $64 million was expended on prosthetics and orthotics for 3.5 million people of all ages who could use them. While we have no reliable data on government expenditures for all devices used by youth, we estimate they are on the order of $20 to $30 million per year. Nearly all agencies serving handicapped youth expend some funds on devices, but no agency has major responsibility for perfecting and disseminating these aids. Our investigation suggests that considerable progress has been made in creating new aids, but that many of these are not being developed from the working prototype to the user-engineered, final product stage; mechanisms for getting the equipment to the consumer need improvement.

Recreation/Social Activity

This service, obviously a vital contributor to the quality of life of handicapped youth, is provided as a fringe benefit of the education service, but is not now a government responsibility.
Personal Care

While almost all handicapped youth care for themselves or are cared for by their families, there are four principal exceptions: $747 million was spent in 1970, primarily by the states, for residential inpatient care of a quarter million mentally handicapped youth; some small fraction of the special education funds went for residential schools; a portion of the health budget went for personal care in hospitals or for visiting health workers; and a small portion of the welfare budget paid for personal care in foster homes.

Income Maintenance

This is one of the largest services in terms of expenditures. In 1970, welfare agencies spent some $635 million to aid about one million handicapped youth. The Federal contribution to this total was about one-half. Prior to the Social Security Amendments of 1972, most youth given aid were eligible not because of their handicap, but because they were part of a family receiving Aid to Families with Dependent Children. The 1972 amendments permit youth from needy families to draw increased aid based on the existence of a handicap under the new combined Supplementary Security Income program providing aid to the aged, blind, and disabled.

Personnel Training, Facilities Construction, and Research

These three services benefit handicapped youth indirectly over the long term by improving the ability of the general system to provide the types of services discussed above. Nearly all research is funded by Federal sources whose total budget in 1972 for research related to handicapped youth, including some funds for research related to the handicapped of all ages, was about $120 million. The largest component was health-related research. This figure represents about 8 percent of Federal and 2 percent of all governmental expenditures for handicapped youth. Research programs are composed of many projects that are not generally youth-specific, which in some cases overlap one another considerably, and whose results are only slowly and partially incorporated into the service system.

Approximately $80 million of the Federal budget went for training of service personnel in professions to aid handicapped youth, and a considerably smaller amount went for construction of service facilities. In practical terms, the Federal Government plays a minor part in the direct financing of facilities construction.

PROBLEMS OF THE PRESENT SERVICE SYSTEM

With nearly $5 billion expended by all levels of government annually, handicapped youth are receiving many needed 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 children and youth have very beneficial effects; however, the system faces major problems.
To ascertain problems, we tapped published material and agency data files, utilized a mail questionnaire soliciting views on problems from every major state agency serving handicapped youth in all 50 states, and interviewed dozens of families having handicapped children. To uncover and better understand problems, we looked at the system from a number of perspectives: those of the Office of the Secretary of Health, Education and Welfare; those of the state and Federal operating agencies; and those of the handicapped person and his family. We also looked at the service system disaggregated by agency, type of service, type of handicap, severity of handicap, age of the youth, geographic location, program, objectives, roles the Federal Government plays, and the functional mechanism used to implement the Federal program. Each view and disaggregation adds a different and important perspective to the problems summarized below and documented in the full report.

Problems described throughout the full version of this report can be grouped into five major classes, each of which is described below: (1) inequity, (2) gaps in services, (3) insufficient knowledge, (4) inadequate or deficient control, and (5) insufficiency of resources. Obviously these are not new problems, nor are they unique to this system. But from several different perspectives, they are critical and demand full examination. To begin this task, we compiled most of the available data to document their existence and extent; to complete this task, we will analyze these and other data to determine what might be done to resolve the problems.

Inequity

If one accepts the premise that federally supported services should be distributed fairly to the population in need, then, by any reasonable standard of fairness, a great deal of inequity exists 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 across agencies. Within states, the preschool children and rural youth are short-changed by the service system, as are certain classes of urban children.

For example, consider the vocational rehabilitation program: In 1970, the number of youth rehabilitated per 100,000 of the general population aged 14 to 21 ranged from less than 100 per 100,000 in some states to over 500 per 100,000 in other states; and VR program expenditures per youth rehabilitated varied across the states from $800 to $4500. Next, consider the special education program area: The estimated portion of the handicapped youth aged 5 to 17 being served varies across the states from less than 20 percent to more than 90 percent, and the portion served varies among the types of handicaps from less than 25 percent of the hard-of-hearing or emotionally disturbed up to more than 75 percent of the speech impaired. Special education expenditures per youth served vary across the states for all handicaps from a minimum of $168 to a maximum of $2463. In some programs, there is an apparent tendency to "cream off" and serve the less severely handicapped youth (i.e., those requiring fewer services and having greater potential for success). Vocational rehabilitation and special education are cited as examples, not because they are worse than other programs, but because data are available on these two programs.
Gaps in Services

Certain critical types of services are neglected and underdeveloped, particularly the prevention service, the identification of those needing service, and the direction or referral service. We know, for instance, that in many geographic areas actual gaps exist in available services; however, without a meaningful local direction service there may be gaps in the mix of services actually provided to meet a child’s needs, even if a full range of services actually exists. The present institutional emphasis on single types of services sometimes does not meet a handicapped person’s total needs. Many services, which are usually the “underdeveloped” ones, are not the prime responsibility of any one agency. Other gaps exist regarding age (e.g., preschool deaf children are not receiving services important for their language development) and type of handicap by state (e.g., eligibility exclusions deny services to some types of children in one state, while in an identical type of program in a neighboring state different exclusions exist). The problem of an inadequate classification system for handicaps, with respect to needed services, also results in gaps or inappropriate services delivered to individuals.

Insufficient Knowledge

Management improvements in most program areas are hampered by lack of reliable data related to 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, occasional 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 efforts 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 what for whom or with what effect.

Inadequate Control

The vast system providing services to this Nation’s handicapped children 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 enabling legislations contributes to a situation in which no one individual or group of individuals 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; and as a result, accountability is generally very weak.

Agencies responsible for a service sometimes do not even have control over the flow of funds for that service; e.g., only about half of the Federal funds for educational services for the handicapped flow through the U.S. Bureau of Education for the Handicapped. Interrelations among agencies at the management level are often perfunctory at best, and in some areas responsibilities overlap considerably. For
example, the Crippled Children's Service and the Medicaid program both fund medical services for needy handicapped youth, but generally do so without benefit of formal 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. Lack of control at the level of the individual service recipient is evidenced by the neglected and highly underdeveloped direction or referral service for matching the needs of the handicapped person with the appropriate mix of locally available services.

**Insufficient Resources**

Current resources devoted to services for handicapped youth are clearly insufficient, if service to each person in need is the criterion. Large unmet needs exist; for example, in the special education area less than 60 percent of those in need are served. Inadequate resources (dollars, personnel, and facilities) was the problem most often cited in previous studies and reports, by special commissions, by officials in the agencies 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 mixes of services delivered, and the institutional structure even if the present funding levels are not increased.