

DOCUMENT RESUME

ED 087 157

EC 061 140

AUTHOR Kakalik, James S.; And Others
TITLE Services for Handicapped Youth: A Program Overview.
INSTITUTION Rand Corp., Santa Monica, Calif.
SPONS AGENCY Department of Health, Education, and Welfare, Washington, D.C. Office of the Assistant Secretary for Planning and Evaluation.
REPORT NO R-1220-HEW
PUB DATE May 73
NOTE 352p.

EDRS PRICE MF-\$0.65 HC-\$13.16
DESCRIPTORS Agencies; *Exceptional Child Education; *Government Role; *Handicapped Children; Institutions; *Program Evaluation; *Services
IDENTIFIERS Delivery Systems

ABSTRACT

Presented is the Rand Corporation's cross-agency evaluation of government programs which serve approximately 9 million mentally or physically handicapped youth aged 0 to 21 years. Programs are grouped into areas by the five types of agencies administering them: health, education, welfare, vocational rehabilitation, and mental health and retardation. Services provided are said to include prevention, identification, direction to service providers, counseling, medical treatment, education, special training, vocational training, job placement, creation and provision of special aids or equipment, recreation and social activity, personal care, income maintenance, training of personnel, construction of facilities, and research and development. It is reported that nearly 5 billion dollars are spent annually on services for the handicapped. Provided is a descriptive overview of the population of handicapped youth, the structure and functioning of the service delivery system, current state and Federal service programs, and resources devoted to various categories of handicapped youth. Identified are major problems of the present service system, both in the services delivery systems and in the institutional structure of the programs. Noted are recent expansions of federal, state, and local government service programs and expenditures. Discussed are major problems such as inequities of services, gaps in service, insufficient knowledge, inadequate or deficient control, and insufficiency of resources.
(Author/DB)

SERVICES FOR HANDICAPPED YOUTH: A PROGRAM OVERVIEW

PREPARED FOR THE DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE,
OFFICE OF THE ASSISTANT SECRETARY FOR PLANNING AND EVALUATION

JAMES S. KAKALIK GARRY D. BREWER
LAURENCE A. DOUGHARTY
PATRICIA D. FLEISCHAUER SAMUEL M. GENENSKY

R-1220-HEW
MAY 1973

U.S. DEPARTMENT OF HEALTH,
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PREFACE

This 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 report concentrates on the first purpose. Another report, to be completed in December 1973, will concentrate on the second purpose.

An abridgment of this report, R-1220-HEW (Abridged), is also available, summarizing the major findings.

SUMMARY

This is 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 auditorially 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 a wide variety of services. This report provides a descriptive overview of the population of handicapped youth, the structure and functioning of the system, 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.

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 the typing of the manuscript. P. Y. Hammond and E. S. Quade reviewed and made helpful comments concerning earlier drafts of this report. We are grateful for their assistance.

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GLOSSARY

AB	Aid to the Blind
ADA	Average Daily Attendance
ADM	Average Daily Membership
AFDC	Aid to Families with Dependent Children
APTD	Aid to the Permanently and Totally Disabled
BEH	Bureau of Education for the Handicapped
CCS	Crippled Children's Service
CMHC	Community Mental Health Centers
C&Y	Children and Youth
DHEW	Department of Health, Education and Welfare
EHA	Education of the Handicapped Act
ESEA	Elementary and Secondary Education Act
GA	General Assistance
HSMHA	Health Services and Mental Health Administration
ITEB	Income Tax Exemption for the Blind
MCHS	Maternal and Child Health Service
M&I	Maternal and Infant Care
NEI	National Eye Institute
NHLI	National Heart and Lung Institute
NIAID	National Institute of Allergy and Infectious Diseases
NIAMDD	National Institute of Arthritis, Metabolic, and Digestive Diseases
NICHD	National Institute for Child Health and Human Development
NIDR	National Institute of Dental Research
NIGMS	National Institute of General Medical Sciences
NIH	National Institutes of Health
NINDS	National Institute for Neurological Diseases and Stroke
OAA	Old Age Assistance
OASDHI	Old Age, Survivors, Disability, and Health Insurance
SRS	Social and Rehabilitation Service
SSA	Social Security Administration
SSDI	Social Security Disability Insurance
VE	Vocational Education
VR	Vocational Rehabilitation

PART 1

SERVING HANDICAPPED YOUTH: A "CRISIS OF CONTROL"

This part of the report presents an overview of current service policies, programs, and their problems, along with a discussion of the issue of goals and performance, and a way to map the system serving handicapped youth. Many problems identified in this system are also the problems of the entire human service sector of our society. In the words of a former Secretary of DHEW:

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)," *A Report on the HEW Potential for the Seventies*, U.S. Department of Health, Education and Welfare, January 18, 1973.

1. INTRODUCTION

This is 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 auditorially 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 1.1., we believe that they do represent the correct order of magnitude regarding individuals who require at least some special services. Appendix A discusses these and other estimates and definitions.

SCOPE OF THE RESEARCH

This report focuses on existing Federal and state programs providing services to all types of mentally or physically handicapped youth, giving a descriptive overview of those programs and many of their problems and covering the following subject matter:

Table 1.1

ESTIMATED NUMBER OF HANDICAPPED YOUTH AGED 0-21 IN 1970

Type of Handicap	Number of Youth	
Visual impairment		193,000
Partially sighted	180,000	
Legally blind ^a	45,000	
Hearing impairment		490,000
Hard of hearing	440,000	
Deaf	50,000	
Speech impairment		2,200,000
Crippling or other health impairment ...		1,676,000
Mental retardation		2,800,000
Emotional disturbance		1,500,000
Learning disability		740,000
Multihandicapped		50,000
Total		9,550,000

^aIncluding 32,000 partially sighted.

- 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 study will be expanded to include local and private programs, as well as those of the Federal and state governments.

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 have 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.

- 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.

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.

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 other words, we have looked at the system both from the “top down” and the “bottom up.” In doing so, we have identified problems not commonly known nor 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 of them 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 basic sources: a survey questionnaire mailed to several major service agencies in each state (over 300 agencies in all); interviews with officials in over 60 different Federal and state agencies; Federal and state reports and unpublished data on specific programs; existing literature on the field; and an interview survey of handicapped service recipients.

The *questionnaire to state agencies* was designed to collect information on program costs, the composition of program resources, the services delivered, and the size and character (age, race, income, handicap) of the population served, and on problems of the service system. The response rate was 60 percent; of those not responding, some 33 percent explained why they did not or could not respond, and reasons for non-response have been analyzed and presented in Appendix B. The

questionnaire was mailed to every agency providing a major service program for handicapped youth. Agencies varied from state to state, but typically included departments of education, public health, mental hygiene, mental retardation, welfare, and vocational rehabilitation. Appendix C presents a list of those receiving the questionnaire. Sample copies of the questionnaire are contained in Appendix D.

Interviews were conducted with state and Federal officials who administer programs for the handicapped. In these interviews, we concentrated on gathering background materials on programs and on problems, and on identifying where information gaps existed and might be closed by use of the questionnaire and other means. Interviews with state personnel in Arkansas, California, Illinois, Massachusetts, and Wyoming helped develop and field test the questionnaire and provided more candid appraisals of the system than a mail survey alone would have achieved.

We used numerous *Federal reports and data*, but many are not published. In several cases we could only obtain raw computer data tapes or summary listings from which we did our own tabulations and analyses. In several instances, we tabulated program data from paper records kept in an agency's files.

The literature dealing with all facets of the handicapped is vast. We collected about 1000 titles, only a small fraction of the extant material on the handicapped. But most of the untapped literature is not highly relevant to the type of policy problems that state and Federal officials face, because it is too specialized or too technical to be of much use in the broader planning context of program administration. Especially useful research is described at the end of Secs. 5 through 10, which describe the service agencies. And our bibliography cites many other documents helpful in our work.

The service system description would be incomplete without *information from the consumers* about the quality and quantity of services that they receive. Our second report will document the results of this phase of the research; however, Appendix E discusses the survey design, the questionnaire, and some preliminary illustrative findings.

STRUCTURE OF THIS REPORT

This report is divided into three parts: the first, "Serving Handicapped Youth: A Crisis of Control," summarizes current service policies, programs, and their associated problems (Sec. 2); gives various means of mapping and comprehending the system serving handicapped youth (Sec. 3); and discusses goals and performance issues (Sec. 4). The second part, "Current Service Policy," contains a more detailed overview of each major service program (Secs. 5 through 10). The third part, "Next Steps in the Research" (Sec. 11), briefly discusses the planned program evaluation for the auditorially and visually impaired youth that will comprise our final report.

We have used a three-level structure to present information on the current service system for handicapped youth. The first level is that of the single program, as described in Secs. 5 through 10. The second level overviews all programs in a given

type of agency (e.g., vocational services, education, welfare, health, and mental health and retardation agencies) in the "Summary and Overview" subsections of Secs. 5 through 10. Finally, the third level combines all government programs and agencies; Sec. 2 presents an overview from this level.

2. PROGRAMS, SERVICES, AND PROBLEMS OF THE PRESENT SERVICE SYSTEM

INTRODUCTION

Before describing the programs, services, and problems of the present system serving handicapped youth, this section briefly characterizes discernible institutional roles for the Federal Government in terms of four models. These are the most generalized part of an intellectual "map," described fully in Sec. 3, that also defines the service system in terms of functional mechanisms, rationales, policy processes, and objectives.

The basic models have several dimensions: operations, policy and program control, dollars, and innovation/stimulation. While we do not claim that a given operating institution conforms exactly to any one model, describing the pure model types helps to locate specific governmental institutions within the context of the larger system.

Model I: Direct Operations

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 is playing a comprehensive role termed "Direct Operations," since it is the direct service delivery that distinguishes this model from the other three.

Model II: Controllership

This model is the same as the Direct Operation model except that subordinate agents such as the states and localities deliver the actual services according to carefully prescribed guidelines and subject to authoritative evaluation.

Model III: Special Revenue Sharing, Plus

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 all characterize the "Catalytic" model, whereas direct service provision, service funding, and service policy control do not.

THE PROGRAM VIEWPOINT

This report describes over 50 different major identifiable Federal programs¹ 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. Many programs are not discussed here because they involve low expenditures, affect 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 chose to group the programs into areas by the five different types of agencies that administer them: vocational rehabilitation, education, welfare, health, and mental health and retardation.

Figures 2.1 and 2.2 show, by type of agency, 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 more than half of the expenditures, followed by mental health and retardation, and welfare agency programs. The Federal expenditures of an estimated \$1.1 billion annually comprise 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 retardation, whereas Federal funding predominates for health and vocational services. Welfare is about evenly divided between Federal and non-Federal funding.

Figure 2.3 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

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).

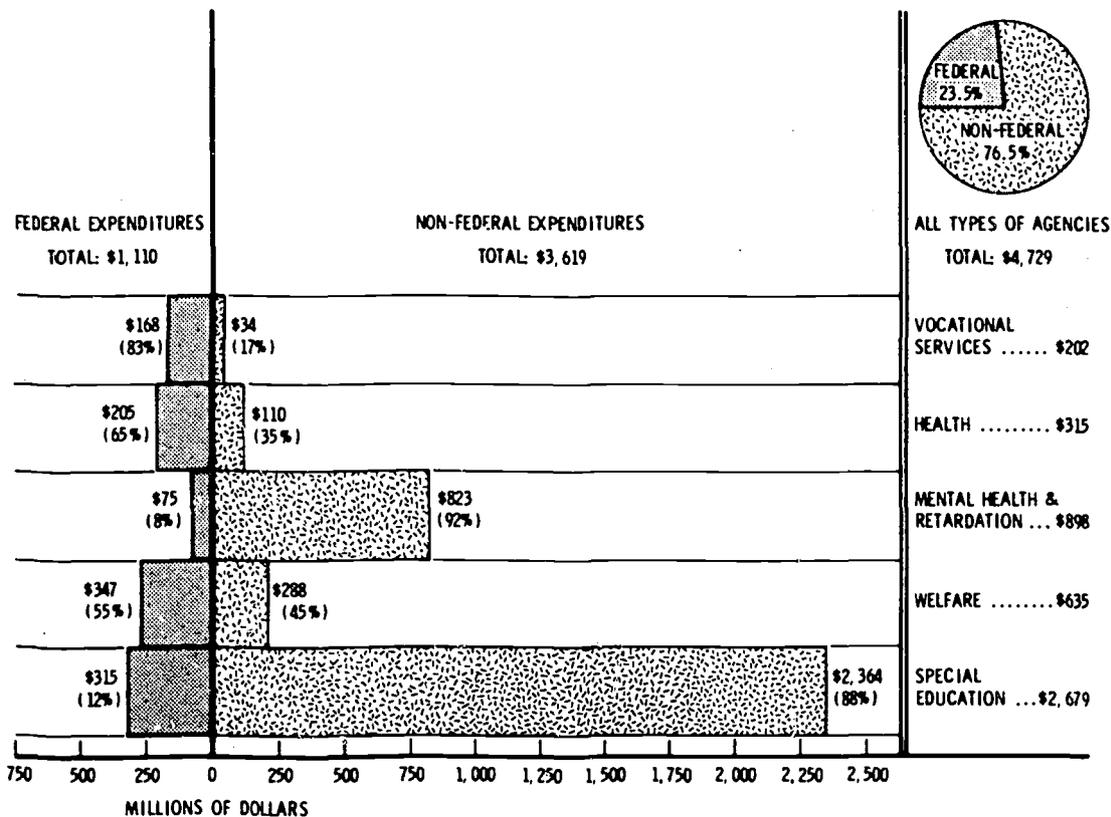


Fig. 2.1—Government expenditures for handicapped youth

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 aged 0 to 21 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 2.4 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. 2.4 are per handicapped youth, not per handicapped youth served. Funds expended per handicapped youth served are considerably higher, as described below.

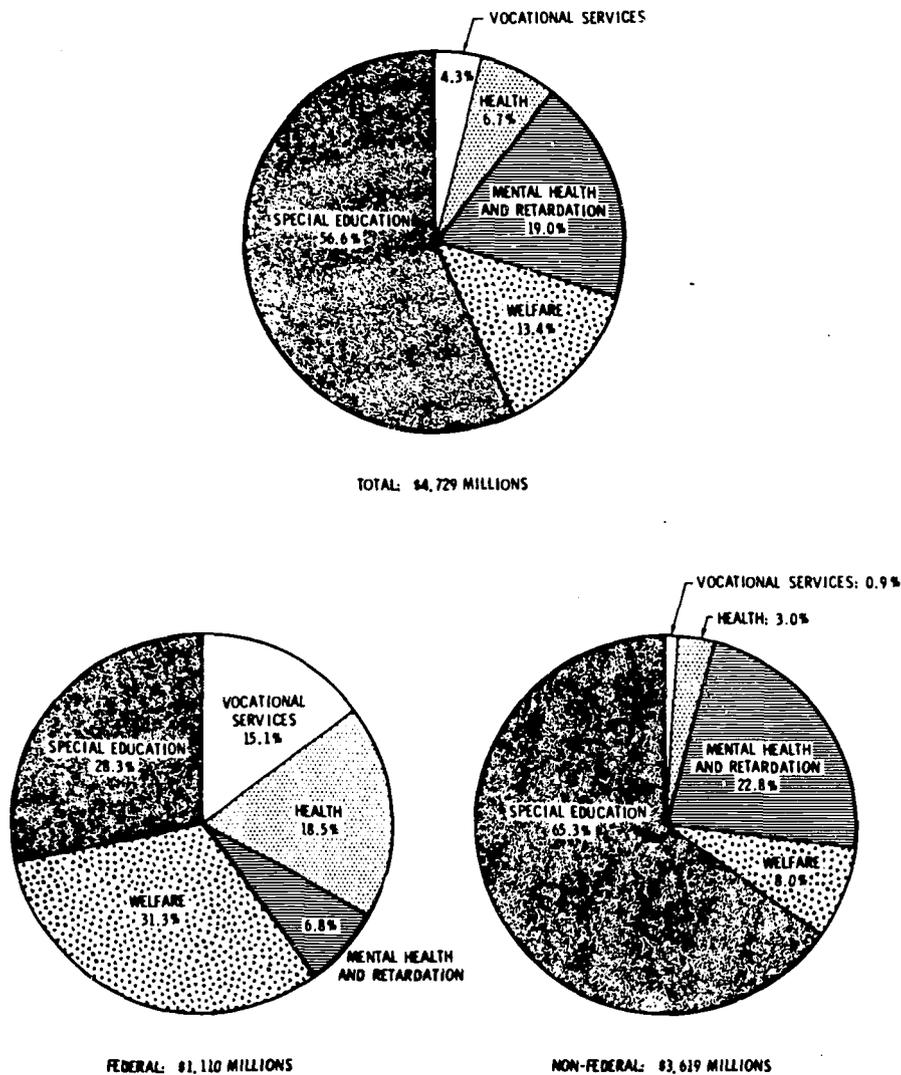


Fig. 2.2—Percentage of government expenditures for handicapped youth by type of agency

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 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 expenditures 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

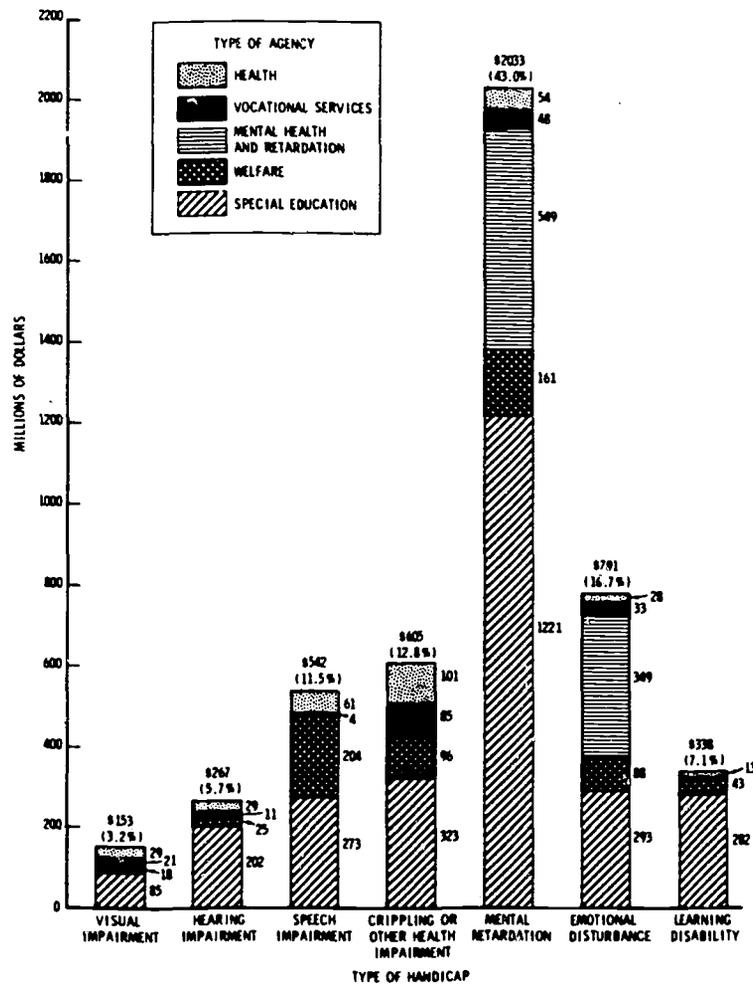


Fig. 2.3—Government expenditures by type of handicapped youth and type of agency

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, for 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.

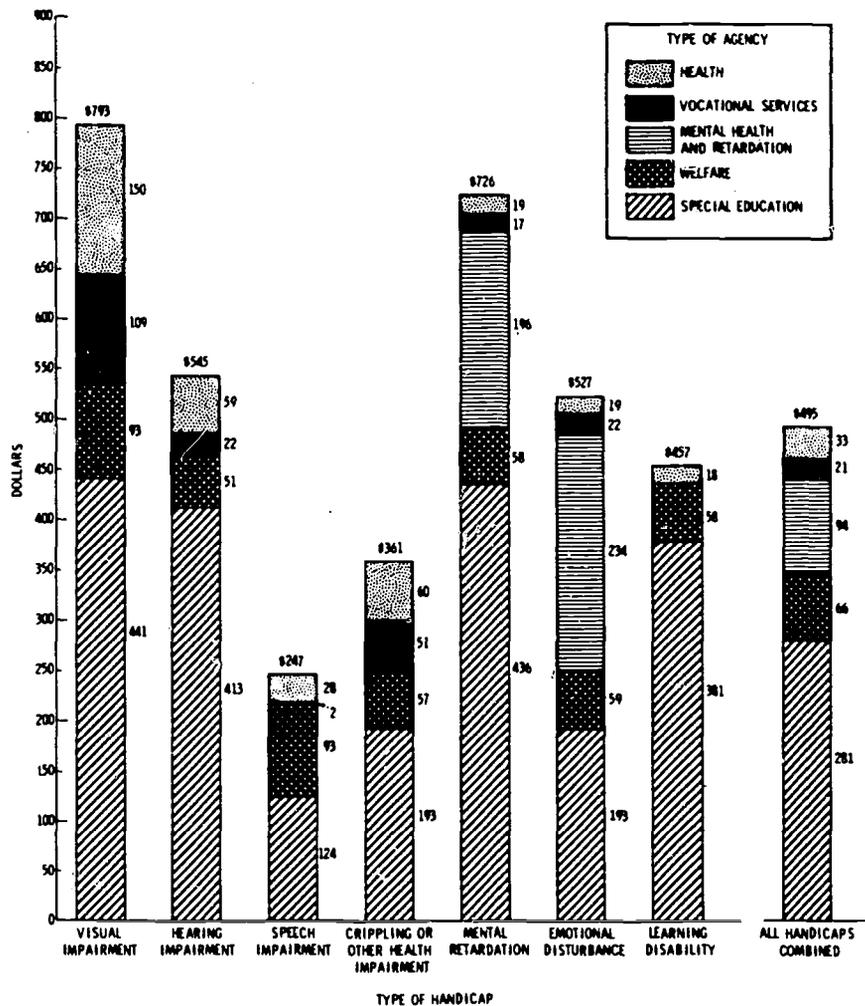


Fig. 2.4—Government expenditures per handicapped youth by handicap and type of agency

When a program also serves clientele who are not mentally or physically handicapped or not 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 (BEH) 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-à-vis the states is not a dominant one, but appears to be a hybrid and changing one which is now 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, because such 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, 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 Operations 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 pro-

gram, 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 composed of the following features, each of which is described below: (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 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 2.1. 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 2.1 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, as we point out later.

To understand the services better, let us review each briefly.

Table 2.1
SERVICE COMPONENTS OF FEDERAL AND STATE AGENCY PROGRAMS
FOR HANDICAPPED YOUTH

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

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

Prevention

Specific precautionary measures are effective in preventing certain handicapped conditions. Rubella and other immunizations are excellent cases in point. Prevention, however, is a neglected service that no one agency has major responsi-

bility 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 universal 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 isolat-

ed 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 in that year. 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. 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 Supplemental 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 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 the nearly \$5 billion expended at 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.

Problems described throughout 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 portions of the handicapped youth aged 5 to 17 being served vary 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, they 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 who is doing 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 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.

3. MAPPING THE SERVICE SYSTEM: MODELS, FUNCTIONS, RATIONALES, AND THE POLICY PROCESS

INTRODUCTION

This section presents the intellectual "map" we devised to locate and describe large pieces 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 help produce services. To provide a sense of why the system functions as it does, we postulate *rationales*, both implicit and explicit, being advanced to justify the selection of broad classes of functional activities constituting policies and programs. And, finally, we lay out key *processes* by which the system appears to operate and change by way of detailing a general sequence of events through which policies and programs are created, implemented, and eventually ended.

MODELS OF FEDERAL INSTITUTIONAL ROLES

At least four separate institutional roles (models) 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 for defining the basic models: operations, policy and program control, dollars, and innovation/stimulation. Each dimension is a metric indicative of the 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? Policy formulation and program evaluation are key examples.

- *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 primarily responsible for creating new ideas, programs, and policies and for encouraging operational agencies to adopt practices and procedures reflecting these ideas? Research, development, demonstrations, and so-called "social experiments" are all illustrative activities.

Each dimension will become clearer as we characterize our four basic models.

Model I: Direct Operation

If a single institution (or collection of institutions all related to the same service area, e.g., Federal special education programs for the deaf-blind) is the primary locus for dollar support, policy and program formulation and monitoring, service delivery, and new developments, then that one institution or cluster of related institutions is playing a comprehensive role which we term "Direct Operation," because it is the direct service delivery that distinguishes this model from the following ones. The primary idea is that all responsibility and authority are concentrated in one or a few institutional entities. National defense is one such substantive area; the Bureau of Indian Affairs' responsibility for care and support of the Indian population is another; and certain selected aspects of Federal participation in special education and Social Security activities provide yet other, more narrowly focused instances.

Given the size of the country's population, the diversity of its needs, and the complexity of programs that have sprung up to satisfy those needs, there is increasing awareness that universal rules and the Direct Operation modus operandi by the Federal Government may do more harm than good in some program areas.

The detailed administrative approach does not work for clear enough reasons—which start with the impossibility of writing detailed rules to fit every case, and end with the lack of highly trained people to administer every case, assuming that an administrative solution is possible.¹

The issue seems to boil down to the simple question, "Is it a good thing for the Federal Government to take on the direct responsibility for a certain service to a subpopulation?" If one is not convinced that the program will run better when Washington runs it, then there is a need to examine alternative structural models.

Model II: Controllership

"Controllership" reduces the extent of operation (direct service provision) but retains the remaining three dimensions. In this model actual service provision is delegated or otherwise turned over to some other institution (i.e., subordinate agencies such as the states and localities), but determinations of what to spend money on, how to spend it, and how to account for it are concentrated in one definable Federal unit, as are the powers to allocate enabling resources and to create and generate new approaches to manage the underlying problems. The Community

¹ R. A. Levine, "Rethinking our Social Strategies," *Public Interest*, Winter 1968, pp. 88-92.

Mental Health Centers (CMHC) program of the National Institute of Mental Health has most characteristics of this model: it is funded primarily with Federal dollars; Washington promulgates its policies and guidelines; innovations and new ideas evolve as a result of a separate provision of the basic Federal legislation; but the states and localities provide the services themselves. Many of the shortcomings, although not all, of the Controllership model are shared by the CMHC as well.

An inherent general problem with the Controllership model is its reliance on centralized financial coercion and its consequent lack of primary responsibility for those actually delivering the services. Often with this model, local officials, who know the most about the clients and their problems, are governed by complex and constricting rules handed down from higher bureaucratic levels. This causes clients who do not conform to the rules or qualify for fixed categories to be shunted from one agency to another; and it often makes it difficult to fix responsibility. Because those who actually deliver the services know they will be "blamed" for inadequate or poor performance, they tend to be unwilling to act in daring or creative ways.² It is a structural model and form of reasoning that has caused many organizations to limit themselves to administrative functions. When a hierarchy such as that implied in the Model II characterization prevails, leaders tend to impose what they consider rational guidelines on their subordinates without adequately considering the experiences of those who must put the policies into practice, a problem that is particularly severe, for example, in mental hospitals, but one that also exists in schools and in welfare systems.

Model III: Special Revenue Sharing, Plus

We use the term "special revenue sharing" in its *de facto* not its *de jure* sense.³ Dimensions concentrated in this model are control over *broad* policy formulation and specific program evaluation and responsibility for innovative and stimulative activities. There is less direct service provision and drastic altering of the resource flow once initial allocations have been made. Broad policy formulation means that some intended recipient populations will be generally identified as likely beneficiaries of services, but more specific guidance than this will not be imposed; i.e., there will be no copious guidelines, no detailed programs, and minimal detailed concern for how resources actually are expended. The implicit idea is analogous to the private sector practice of leaving operational responsibility to a plant manager whose performance is then periodically assessed relative to other plant managers and to some absolute norm such as a profit and loss statement. The obvious difficulties involved in measuring public sector goods and services and the absence of any social balance sheet are not to be underestimated.⁴

² V. A. Thompson, *Modern Organizations*, Alfred A. Knopf, New York, 1965, pp. 129-137.

³ While initiatives to institute special revenue sharing in the educational, health, and social service areas are all awaiting formal adoption, *in fact* a number of identifiable programs already exist that share characteristics which could best be described as revenue sharing. How these programs have fared may provide a valuable preview of how the larger proposed programs may eventually develop and fare as well.

⁴ Worth Bateman, "Assessing Program Effectiveness," *Welfare in Review*, Vol. 6, January/February 1968, pp. 1-10; Peter Rossi, "Practice, Method, and Theory in Evaluating Social Action Programs," in J. L. Sundquist (ed.), *On Fighting Poverty: Perspectives from Experience*, Basic Books, New York, 1969, pp. 217-234; Jerome Rothenberg, *The Measurement of Social Welfare*, Prentice Hall, Englewood Cliffs, New Jersey, 1961; and J. S. Wholey et al., *Federal Evaluation Policy: Analyzing the Effects of Public Programs*, The Brookings Institution, Washington, D.C., 1970.

We know that the Federal Government is able to collect taxes and to disburse funds efficiently; but some people are learning that it is less able to run large, detailed programs, or at least it does this far less effectively than taxing and disbursing. What this implies is an evolving trend to increased reliance on revenue sharing types of operations; however, it also implies that there are significant unrealized needs to account for performance.

The "Plus" in the Model III label elaborates the concept of "minimal Federal concern" by developing the notion that the Federal Government has some right and obligation to evaluate the performance of service-providing agencies to whom it supplies special revenue sharing. Where are the significantly effective and ineffective programs, and what might be done to disseminate the former and to discourage the latter? The underlying idea is to improve performance by rewarding those who are in fact "doing a good job," while not specifying in advance the mechanisms by which the job is to be done. When a "good job" is discovered, the reasons explaining why it is so are then liable to be scrutinized and perhaps implemented in other related areas where performance has not been as exemplary.⁵

To counter prevalent fears that transferred funds will be squandered in poorly conceived and operated state and local programs, the evaluation leverage must not be foregone and indeed must be developed to a considerably greater extent than it is at present. This requirement is primarily an informational one. Nowhere else in the system will there be an opportunity to view the "big" or comprehensive picture that is essential before one attempts to structure broad policies. This point is particularly true for our fourth or "Catalytic" model.

Model IV: Catalytic

Research, development, demonstration, and social experiments are all characteristics of the "Catalytic" model. Together they represent investments in intellectual and technical activities designed to improve services and productivity, thereby making scarce dollars go farther or be more effective; to improve operating systems, thereby insuring that services are delivered as efficiently as possible; and to improve the amount and quality of technical assistance available to those in the field, thereby improving the flow of newly created knowledge into the operating environment. The Catalytic model's medium of currency is information rather than money. If successfully carried out, its primary objective insures leadership based on the best knowledge about the system, its problems, and its possibilities. In operational terms, it aids in setting up program objectives and structure, rather than running the programs; it aids in selecting priorities based on solid analyses, rather than throwing money at problems; and it aids in controlling large, complex, and hard-to-understand systems, rather than observing them as they plunge along out of control.

While the total Department of Health, Education and Welfare budget is abso-

⁵ This is not to say that special revenue sharing is a panacea, as evidenced in current second thoughts that many state officials are having about the education aspect of it. See Karen De Witt, "Education Report/Handicapped Schoolchildren Enmeshed in Debate on Federal Role in Education," *National Journal*, February 10, 1973, pp. 199-205. The fundamental issue seems to be whether the amounts forthcoming from educational special revenue sharing will be adequate to meet the states' needs, particularly in light of recent court decisions interpreting the Constitution's 14th Amendment to include the right to an education for all handicapped children. The second thoughts are not about the structural concept of revenue sharing, per se, which has received many favorable initial reactions.

lutely quite large, there is in fact very little discretionary or "controllable" latitude in it. Cash transfer programs, such as Medicaid and the payment of Social Security benefits, are essentially open-ended; i.e., the dollar outflow cannot be reduced short of redefining eligible populations or, in the case of Medicaid, narrowing the range of coverage.⁶ Because discretionary funds are limited, there is consequently a rather severe problem of allocating scarce resources and a need to create alternative bases to maintain power. In this case the new base is information. It is in part because of these demands that we observe considerable interest in the development of the Catalytic model on the part of certain Department of Health, Education and Welfare officials.⁷

In his thoughtful discourse, *The Step to Man*, John Rader Platt has struck the key conceptual features of the Catalytic model in terms of organizations yet to be developed and functions yet to be performed.⁸

But we have no . . . organizations that spend all of their time searching deliberately for new inventions and combinations for the solution of social problems. There is no General Electric, no national laboratory, with full-time research and development teams assigned to come up with ingenious ideas of improved social organization and communication and interaction. . . . The main reason why our solution of social problems lags so far behind our magnificent technology today may be that we have not yet organized the same deliberate search for ideas to deal with them. . . . Yet "social inventions" are possible, as we have seen, just as possible as technological ones, and might be searched for in the same way.

These abstractions may be illustrated concretely and, by doing so later, the possibilities of the Catalytic model shall become clearer.

As discussed later, mental retardation is a pervasive and expensive handicapping condition in this country. One of the saddest facts about mental retardation is that many cases could be prevented or averted if present knowledge could be applied more widely. Unfortunately, this knowledge has not yet produced much practical "fallout" for the bulk of the present and future mentally retarded population. For example, we know how to recognize the chromosomal flaw that is responsible for mongolism (Down's Syndrome) and several other genetically related causes of retardation; we can, with amniocentesis, diagnose the problem in utero. But this knowledge, and the genetic counseling implied by its application, is not widely recognized and practiced. The Catalytic model would attend to this and many other mismatches of knowledge and practice as a first order of business, turning them to the collective advantage.⁹

To illustrate these structural models we have alluded to some general functional mechanisms that might characterize each, but we have not done so systematically. Let us turn now to that task.

⁶ I. J. Lewis, "Government Investment in Health Care," *Scientific American*, Vol. 224, April 1971.

⁷ The Bureau of Education for the Handicapped has increasingly adopted a "Catalytic" posture in recent years, and its efforts bear careful examination.

⁸ J. R. Platt, *The Step to Man*, John Wiley, New York, 1966, pp. 132-133. Platt, in his capacity in the Mental Health Research Institute at the University of Michigan, has thought hard and well about many of the problems of large, uncontrolled social systems and what might be done about them; this book is a testimony to his constructive concern.

⁹ See Peter Drucker, *The Age of Discontinuity*, Harper and Row, New York, 1969, especially Chapter 10, "The Sickness of Government," for some pertinent comments on this general issue.

FUNCTIONAL MECHANISMS

The models just considered lack specific detail. In concentrating on broad structural characteristics, they provide one with an approximate "sense" of the extraordinarily complex system we are describing. Understandably, embedded in the concept of model type are some basic ideas about the functional mechanisms that are used to produce certain fundamental services. For example, the Direct Operation model, by directly providing services, purchases, demonstrations, and so forth, employs practically every functional mechanism available and sometimes monopolizes the production of specific types of services for selected consumer subsets of the population. To gain more than a summary understanding of the system, one must be willing to go to a more finely resolved map to observe more systematically and in greater detail these functional mechanisms, the services they produce or provide, and the rationales generally used to justify both mechanisms and services. The key point is that the models of Federal roles represent only a coarse, general approximation of the system's actual detail and complexity. Better understanding demands finer resolution.

The general functional mechanisms with which Federal institutions in this system help produce a range of definable services or products include (1) the direct provision of services, (2) the purchase of services through state or local government institutions, (3) the regulation of those providing services, (4) the investment in manpower and facilities that in time contributes to an adequate supply of services, and (5) the search for and dissemination of information both about the system, its problems, and its participants and about improved ways to provide services. After discussing the characteristic functions, we shall consider some rationales commonly employed to justify them.

These five mechanisms produce a variety of specific services, as described in Sec. 2, that are the system's "products" as seen primarily from the perspective of the "consumer"—the handicapped child and his family.

Of the five functional mechanisms, the direct provision of services, and the purchase of services through state and local government institutions, are plainly dominant in terms of dollars expended on them, their impact on the affected population, or any other suitable measures; however, the importance of the remaining mechanisms is not to be discounted, particularly since several of them appear to be underdeveloped and may represent strategic, exploitable opportunities.

Direct Provision of Services

Prime examples of services provided directly by the Federal Government are the Social Security Disability Insurance program; the new combined Supplemental Security Income program providing aid to the aged, blind, and disabled program; Gallaudet College; the Kendall and Model Secondary Schools for the Deaf; the National Technical Institute for the Deaf; St. Elizabeths Hospital; and the Indian Health Program. In each of these an agency of the Federal Government, rather than an agency of state or local government, provides services directly.

Purchase of Services

Prevention, medical treatment, vocational training, job placement, and identification are examples of services purchased with Federal dollars through state and local agencies that provide the services directly. In most cases Federal funds are matched by state or local funds according to formulas accounting for demographic and income differentials between states and locales. Immunization is a clear example of the prevention service, and mass screening for a variety of handicapping disorders illustrates the identification service. An example that does not depend exclusively on Federal dollars for medical treatment is the Crippled Children's Service program. Vocational preparation and job placement are given in assorted Vocational Rehabilitation and State Employment Service programs with Federal funds. As noted previously, the Department of Health, Education and Welfare, except for a relatively few discretionary dollars, has little or no control over the spending of its budget. Generally it is the scarcer discretionary funds that flow through the purchase of service programs cited above.

Another example of service purchase, in this case primarily the income maintenance service, is the Aid to Families with Dependent Children program which relies heavily on Federal funds but is operated through state and local agencies. This is part of the larger "uncontrollable" segment of the Health, Education and Welfare budget and hence has profound consequences for the orderly and effective operation of the overall system.

An important point with respect to income maintenance in general is that it provides an indirect means for the government to purchase other types of services, with the discretion of what other services are purchased for the handicapped youth left to the recipient of the income maintenance funds. In actuality, income maintenance is an intermediate or instrumental service that is subsequently convertible into medical treatment, personal care, recreation, and any number of other ultimately consumable services. However, this mechanism has inherent serious system deficiencies. Questions such as, "How many of what kinds of services does the population actually use?" and "What do those services really cost?" have been rendered virtually unanswerable because of the method by which income maintenance is delivered.¹⁰ Also, given the poor quality of publicly available information on who supplies what services at what cost, with what benefit, how can a handicapped youth's family intelligently decide what services to purchase? Income maintenance is a notably large example of a service *not* provided by agencies primarily concerned with handicapped children. Therefore eventual demand for specific, handicap-related services is known less well than it could be; consequently, control over the supply of those services diminishes.

Regulation of Those Providing Services

Regulation involves three conceptually different but related clusters of mechanisms, which depend heavily on the collection and analyses of information about

¹⁰ When, for example, we discuss "Title XIX children" (Sec. 8), the operational result of the functional problem manifests itself in terms of not knowing (1) how many recipients are handicapped, (2) what the handicapping conditions are for those who are afflicted, (3) what the total amount and cost of all services received are, and (4) generally, how well the services received are "doing the job." Program planning and operational control under such a situation are extremely difficult. Thus this problem is not unique to income maintenance.

the system: licensing, certifying, and auditing may be considered as one such cluster; program coordination activities, through all levels of government, may be taken as another; and rulings by the courts as still another.

Licensing, Certification, and Auditing. The licensing of individuals and facilities who provide services is a prime direct means by which governments insure the delivery of products with minimal standard quality. Contributing to the overall effectiveness of service are state and local licensing of special schools and homes used by children in the special education and personal care services; Food and Drug Administration licensing of drugs used in the medical treatment service; and local and national peer review boards that license and certify individuals who provide specialized training and education services.

Certification is ordinarily carried out on behalf of the government by tested and qualified members of professional skill groups, e.g., medical certification boards, education certifying bodies, and so forth. For example, the National Bureau of Standards has recently expanded its activities into the area of sensory aids and some prosthetics, assessing and implicitly certifying the quality, utility, and general "worth" of most commercially available hearing aids.

Auditing, taken narrowly to mean fiscal accountability, is ordinarily done by private firms and individuals who have at some prior time been "certified" to carry out this responsibility. It is also done on a larger scale and with a broader intent by representatives of the U.S. General Accounting Office, and personnel within Federal departments.

Licensing, certifying, and auditing, taken together, represent a "high-leverage," low-cost functional mechanism for influencing the system serving handicapped children and youth.

Program Coordination Activities. Such is not the case, however, for program coordination activities, and data and information management deficiencies are at the root of the problem. Poorly coordinated or uncoordinated service provision is a common theme running throughout this report on the system serving handicapped children and youth. The problem is chronic and stems from program fragmentation and from the lack of information (about all services, programs, and activities affecting the lives of the handicapped) organized in comparable accounting formats to allow comparisons at various levels of comprehensiveness and aggregation. One operational implication of this functional deficiency is captured by Michael Marge:¹¹

But when such information is not available, it is hoped we will be forgiven when we turn, as did the soothsayers of old, to our crystal ball to foretell the future.

The problem is recognized and potential solutions have been offered;¹² but the problem persists, has not been satisfactorily resolved and, as a result, the effectiveness of delivery for a number of our identified services is diminished.

¹¹ When the article was written from which this citation is taken, Michael Marge was the Director, Program Planning and Evaluation, Bureau of Education for the Handicapped, U.S. Office of Education. Michael Marge, "Planning and Evaluation for the Future," *Exceptional Children*, Vol. 34, March 1968, pp. 505-508, quote at p. 608.

¹² Among these solutions, PPBS (Program Planning and Budgeting Systems), Program Planning and Evaluation, and Management Information Systems often play a major role. See, for example, David Novick (ed.), *Program Budgeting*, Harvard University Press, Cambridge, Massachusetts, 1965; and F. J.

Court Rulings. Court rulings can also have great significance vis-à-vis the operation of programs for handicapped youth. For example, recent court rulings in Pennsylvania and other states have been aimed at guaranteeing each handicapped youth the right to an education.

Investment in Manpower and Facilities

Investment contributes generally to the supply of services, such as those identified, in terms of increasing the available stock of qualified humans¹³ and suitable facilities.¹⁴ Accounting for the impacts of these investments is hard enough,¹⁵ and trying to link the investment function directly with each of our other handicapped youth services is even more challenging. Major service areas in which a more or less direct connection to investment may be made include medical treatment, education, special training, and sensory aids/equipment. In the service area of education, for instance, there is a well developed, empirically based literature that concentrates on that connection.¹⁶ The impacts of investment on other services are not as well researched and known, although this represents one of those underdeveloped and exploitable areas we noted earlier.¹⁷

Research, Development, and the Dissemination of New Information

Another functional mechanism, whose impact on the specified services is hard to assess but which figures prominently as being both underdeveloped and exploitable, is the creation and dissemination of information. This is accomplished through research and development, but also includes the dissemination of information on the delivery of services to those operating direct service programs and to the consumer.

The connections between new knowledge and societal change have been consid-

Lyden and E. G. Miller (eds.), *Planning Programming Budgeting: A Systems Approach to Management*, Markham, Chicago, 1967, especially Part IV, pp. 163-262, for general comments on the first "solution"; Edward Suchman, "A Model for Research and Evaluation on Rehabilitation," in M. B. Sussman (ed.), *Sociology and Rehabilitation*, American Sociological Association, New York, 1966, pp. 52-70; and A. J. Kahn, *Studies in Social Planning and Policy*, Russell Sage Foundation, New York, 1969, for pertinent comments on the second. The area of management information systems has a large literature and the new Medicaid Management Information System and several other less comprehensive, more special purpose systems are embryonic efforts to coordinate activities at the DHEW level.

¹³ G. S. Becker, *Human Capital*, National Bureau of Economic Research, New York, 1964, pp. 94, 117-124, 128 is one standard source.

¹⁴ Robert Dorfman (ed.), *Measuring Benefits of Government Investments*, The Brookings Institution, Washington, D.C., 1965, has a number of directly relevant pieces and is a generally good source of information on this matter.

¹⁵ Bureau of the Budget, *Measuring Productivity of Federal Government Organizations*, 1964, gets at the assessment of investment in the public sector services issue. Political and economic discounting problems abound.

¹⁶ Jerry Miner, *Serial and Economic Factors in Spending for Public Education*, Syracuse University Press, Syracuse, New York, 1963; and O. A. Davis, "Empirical Evidence of Political Influence upon the Expenditure Policies of Public Schools," in Julius Margolis (ed.), *The Public Economy of Urban Communities*, Johns Hopkins University Press, Baltimore, 1965, are only two such examples.

¹⁷ What are the operational time lags between periods at which investments in various human and supporting facilities are made and the points of return for each of the services of direct interest to those responsible for handicapped children? How do those time differentials compare with the time frames used by responsible authorities? What are the discount rates? These and a long list of related questions would serve as the basis of any concerted investigations in this area.

ered extensively elsewhere,¹⁸ and mainly involve the development phases of the R&D function¹⁹ and the coordinative aspects of the service regulation function.²⁰ James S. Coleman and several colleagues executed an empirical investigation of information brokerage done in the context of the creation and diffusion of new drugs among medical specialists.²¹

Unmet needs must be sensed, and that primarily concerns the information collection and processing aspect of the research and development and, to a lesser extent, the coordinative aspects of the regulative functions. However, that these functions are underdeveloped and have not worked well in the past is attested to by numerous demonstrations and disturbances carried out by those whose needs are apparently not being met.²²

The research and development mechanism accounts for slightly more than 8 percent of the Federal resources currently expended on handicapped children, and it operates both to create new knowledge, which in turn may improve individual services (either in their supply or their quality),²³ and to learn about the operation of the system, which may lead to improvements in system effectiveness and efficiency.²⁴ Besides activities recognized as research per se, this function includes demonstrations,²⁵ experiments,²⁶ and "seed money" projects (i.e., one-time provision of resources designed to induce continuing support from third parties). Of these, experiments bear closer consideration.

Experiments allow different alternatives to be tested in a relative, realistic setting but at a small fraction of the cost of changing an entire ongoing system.²⁷ Such experiments have great and obvious appeal, but only recently have any signifi-

¹⁸ J. L. Walker, "The Diffusion of Innovations Among the American States," *American Political Science Review*, Vol. 63, No. 3, September 1969, pp. 880-899; and G. D. Brewer, "On Innovation, Social Change and Reality," *Technological Forecasting and Social Change*, Vol. 5, No. 1, 1973.

¹⁹ Elihu Katz et al., "Traditions of Research in the Diffusion of Innovations," *American Sociological Review*, 1963, pp. 237-252; and G. F. Fairweather, *Methods for Experimental Social Innovation*, John Wiley, New York, 1968.

²⁰ Harold Wilensky, *Organizational Intelligence: Knowledge and Policy in Government and Industry*, Basic Books, New York, 1967.

²¹ J. S. Coleman et al., "The Diffusion of an Innovation Among Physicians," *Sociometry*, Vol. 20, December 1957, pp. 253-270.

²² Herbert Kaufman explains this well in his "Administrative Decentralization and Political Power," *Public Administration Review*, Vol. 29, January/February 1969, pp. 3-14. See also J. Q. Wilson, "The Strategy of Protest," *Journal of Conflict Resolution*, Vol. 3, September 1961, pp. 291-303, for a related assessment of the effectiveness with which unmet needs are being sensed and what specific groups of citizens are doing about it.

²³ For example, with respect to the income maintenance service, see L. L. Orr, R. G. Hollister, M. Lefcowitz, and K. Hester (eds.), *Income Maintenance: Interdisciplinary Approaches to Research*, Markham, Chicago, 1971.

²⁴ For the educational service, see C. H. Weiss (ed.), *Evaluation Action Programs*, Allyn and Bacon, Boston, 1972.

²⁵ J. W. Moss, "Research and Demonstrations," *Exceptional Children*, Vol. 34, March 1968, pp. 509-514, outlines the possibilities and the experiences for the special education services as applied directly to handicapped children.

²⁶ The commonly read piece by D. T. Campbell, "Reforms as Experiments," *American Psychologist*, Vol. 24, April 1969, pp. 409-429, provides a good general elaboration of the concept. A specific example of the connection between the R&D functional mechanism "experimentation" and the specific service "vocational training" is H. J. Meyer and E. F. Borgatta, *An Experiment in Mental Patient Rehabilitation*, Russell Sage Foundation, New York, 1959.

²⁷ For a discussion of the relationship between the experimentation mechanism and medical treatment, see W. J. Horvath, "The Systems Approach to the National Health Problem," *Management Science*, Vol. 12, 1966, pp. B391-B395.

cant ones been carried out. Experimentation seems to have a strong "growth" potential within the relatively underdeveloped R&D functional mechanism.

RATIONALES

Rationales—the underlying reasons used to explain and justify the creation and existence of the functional mechanisms and the services they produce—vary widely in number, degree of ambiguity, and means of articulation. These rationales and their characteristic arguments may be simplified into five general types: (1) resource redistribution, (2) economies of scale, (3) internalization of externalities, (4) control and responsiveness, and (5) stimulation.

In short, we are considering questions such as, "What reasons are generally given for providing certain services in a location and not other services?" and "What general rationales are routinely employed to support what kinds of producing mechanisms?"

Redistribution of Resources

Redistributive rationales underlie many specific forms taken by the Federal "purchase of service through state agencies." *Increasing the number and kinds of social goods and services*, such as those provided to handicapped children and youth, is tied by taxing strategies of several sorts to redistributive reasoning.²⁸ Also encountered are appeals to increase the net productivity of human capital by upgrading the working potential of the handicapped segment of the population through direct purchases of services and investments in manpower and facilities.²⁹

Redistributive rationales are intimately related to the functional mechanisms of purchase of services, regulation of service providers, and investment in means of producing services.

Rationales for redistributing resources reflect *equity* concerns in two distinct ways. For individuals, the concept of narrowing income differentials, as between the handicapped and the nonhandicapped, is easily understood and relates again mainly to purchase of service mechanisms. Redress of governmental-institutional service inequities, given variations in wealth among the states and localities, is a common rationalization for formulas in grant programs characteristic of many purchase of service mechanisms; e.g., allowances for "designated poverty areas" are greater than for other areas, and the net effect is redistributive, based on equity considerations.

Public services have long been determined and rationalized in terms of "effective demand," which roughly translates into the visible and pressing demands of

²⁸ R. A. Musgrave, *The Theory of Public Finance*, McGraw-Hill, New York, 1958, Chapter 5, is a standard source detailing this point. For a more thorough technical discussion, see W. I. Gillespie, "Effect of Public Expenditures on the Distribution of Income," in R. A. Musgrave (ed.), *Essays in Fiscal Federalism*, The Brookings Institution, Washington, D.C., 1965.

²⁹ The relevant literature is voluminous but has been summarized in Jacob Mincer, "The Distribution of Labor Incomes: A Survey with Special Reference to the Human Capital Approach," *Journal of Economic Literature*, Vol. 8, March 1970, pp. 1-27.

those who know the service is available. As basically economic rationales have tended to give way to moral ones, however, the idea of unmet need to justify redistributing resources has gained currency. The unmet needs concept may be defined in terms of *sensing* those who are in need and then *accommodating* those individuals, even if they cannot effectively demand service, both by broadening the scope and improving the quality of services provided them. Accommodating unmet needs is an underlying rationale used in many purchases of service arrangements and is basically redistributive in nature. Whereas effective demand was measurable in principle, unmet need is far less so, with the result that assessing performance in satisfying unmet needs is extremely difficult.³⁰

Financial assistance programs are related to the beneficiary's *needs* and *resources*; benefits flow rather automatically once categorical eligibility is established. Depending on who contributes and who receives benefits, income is redistributed. Wondering from whom to whom this income is in fact redistributed, Richard Musgrave has speculated that it is from the middle and lower classes generally to special categories of the lower class.³¹ Whatever the specific effect, financial assistance programs are rationalized primarily on redistributive grounds.

Economies of Scale

The basic idea of scale economies is related to the relative size of units of production, populations, and so forth.³² While many explanations of scale economies have been advanced (including the use of nonhuman resources, the use of standardized parts, the breakdown of complex processes into simpler, repetitive ones, and the specialization of function), for our purposes we are primarily concerned with *specialization* considerations as viewed from two perspectives: those who provide services and those who receive them.

Providing specialized training for teachers of the small population of the deaf-blind is a manpower investment function rationalized by appeal to economy of scale arguments; it is just not as efficient nor as effective to train these few specialists in a variety of programs in every state as it is to bring them together in a very few locations for training. Constructing one or a few specialized state or Federal schools for selected categories of handicapped children could be likewise rationalized; e.g., it is more efficient and effective to have one school staffed by specially trained teachers providing college level education to the severely handicapped deaf than it is to provide facilities for them in every state. Having a few such facilities enhances regulation of service providers as well through mechanisms of licensure, certification, and the coordination of available resources. Critical masses of scarce and specialized research talent and equipment are also often assembled and supported with reference to scale economy arguments.

³⁰ Points made in this discussion have been made well in another context by Heinz Eulau, "Skill Revolution and Consultative Commonwealth," *American Political Science Review*, Vol. 67, No. 1, March 1973, pp. 169-191, at p. 185.

³¹ R. A. Musgrave, *Fiscal Systems*, Yale University Press, New Haven, 1969, pp. 349-350.

³² The literature on the general subject is extensive, but for two well known, representative efforts see, for example, W. Z. Hirsch, "Determination of Public Education Expenditures," *National Tax Journal*, Vol. 13, No. 1, March 1960; and H. E. Brazer, *City Expenditures in the United States*, National Bureau of Economic Research, New York, Occasional Paper # 66, 1959.

From the perspective of service recipients, this type of rationalization is often invoked in support of the direct provision of services—for instance, room and board expenses incurred by residents in a special school. The argument is that it would be more expensive to serve the individual as well in a nonspecialized setting. The argument depends on the presumption that the individual in question has some legitimate claim to be served at all, or as well.³³ Gallaudet College, the National Technical Institute for the Deaf, and other specialized schools for handicapped children are all to some degree rationalized on these grounds.

Internalization of Externalities

Many benefits of government programs are received beyond the bounds of the political jurisdiction supporting the program. These benefits are termed "externalities" from the viewpoint of the supporting jurisdiction. When the externalities are large and of positive value, there typically will be less investment in the program than would be socially optimal. This can be made clear by way of example. Assume that a local school district could conduct a research program to develop a medical and educational treatment program for autistic children that was effective in bringing them back into normal society. If the cost were \$1,000,000 and there were very few autistic children in the local district, it is doubtful that the district would proceed with the program. The local benefits would be too small when compared with the cost. If the program were expanded nationwide, however, the research and development costs of one million would be small compared with the potential nationwide benefits. If the Federal Government were to fund the research program, the externalities as viewed by the local district would be internalized as viewed from the national level, and the proper incentives would exist for reaching the socially optimum level of investment in the program. This same rationale is also used in urging Federal Government support of training. Many states are hesitant to invest heavily in training professional personnel (e.g., physicians, lawyers, etc.) who then often migrate to another state. Again externalities exist that can be internalized by broadening the political jurisdiction from the local or state level to the Federal level.

Control and Responsiveness

Arguments related to control and responsiveness rationales revolve around (1) the maintenance of standards of service quality, (2) fair provision of services, and (3) the appropriate level of governmental responsibility associated with the production of services.

Quality control arguments are frequently offered in support of regulatory functions. Such arguments take the following representative form: It is the job of the Federal Government, and specifically the Food and Drug Administration, to insure uniform minimal quality of some class of pharmaceuticals as a means of protecting the health and safety of all citizens; or the National Bureau of Standards must assess

³³ However, counter-rationalizations are invoked in support of moves to reduce or do away with provision of service in the form of specialized schools. The argument in this case sometimes takes on the form: Specialized schools are too expensive for the numbers they serve and hence should be abolished. Questioned implicitly in the process is the legitimacy of claimant demands for specialized services.

the relative performance characteristics of sensory aids. Often appeals to quality and uniformity of standards are offered in support of manpower and facilities investments as well. And, finally, the promulgation of guidelines is often couched in quality maintenance language.

Minorities and other special interest groups have long realized that their demands are more responsively met at some levels of government than at others, and hence a number of functions related to those demands are supported by responsiveness rationales. The issue of *oversight*, both legislative and executive, is commonly involved in this instance.

A variant of this responsiveness theme, and one that is more implicit than explicit, concerns the relative "visibility" of the service budget and the related *political* externalities it may create. Suppose that a particular service, such as comprehensive recreation programs for the mentally retarded, were proposed in the budget of some locality. As compared to the total budget, this proposed program may be a large enough proportion to gain visibility and hence be subject to extraordinary political scrutiny. Why should a local politician run the risk of paying a political cost for his promotion of such a program when he has little likelihood of reaping commensurate benefits—i.e., increased or at least undiminished political support? On the other hand, taken as a proportion of the total Federal budget for the mentally retarded or, better still, for all the handicapped, the aggregate of all such recreation programs would probably be small enough that it would not attain "visibility," and hence would have a greater probability of being accommodated. The illustration is not as far fetched as it initially appears, and it goes part of the way toward answering our opening question about why some services are produced in certain places, while others are not.

Debates about the appropriate level of responsibility to conduct or produce a variety of services take a number of characteristic forms, all of which are essentially concerned with control and responsiveness. For instance, one such form might be as follows: It is the responsibility of the Federal Government to train doctors, researchers, or whoever, and to conduct research and development; if the Federal Government does not do it, then it will not get done at all. Or this alternative form is sometimes encountered: It is the responsibility of the Federal Government to respond to those suffering from catastrophic problems, e.g., chronic renal failure, severe congenital heart disorder, and others; if it does not respond, then no one will. Counterarguments exist, of course, and normally question either the premise which legitimates a claim to service or the one that sets the level at which the overall system should be responsive. Debate on decentralization-centralization is the standard medium for this latter issue.³⁴

Innovation: Stimulation/Diffusion

This twofold rationale for providing seed money, initial construction and staffing funds, and disseminating information is basically that states and locales may desire to improve the service system but (1) because of lack of start-up funds

³⁴ Kaufman takes the matter up as does W. E. Moore, *The Professions: Roles and Rules*, Russell Sage Foundation, New York, 1970, pp. 167ff.

or political inertia, they have difficulty in doing so, or (2) because of lack of available knowledge about improved ways of providing services, they cannot do so.

Rationales, being as they are arguments or appeals to marshal support or to justify actions, take on numerous, seldom unambiguous, and often contradictory forms. For instance, every one of the control and responsiveness rationales commonly used could themselves be interpreted in terms of the rationales presented in earlier subsections. They are nevertheless commonly used, important, and must be taken systematically into account if our hopes are to comprehend a system as complex as that providing services to handicapped children and youth. Table 3.1 summarizes the foregoing discussions. The table's basic message is that just as many or more rationales exist for regulation, investment, and research and development functional mechanisms (the relatively "underdeveloped" three) as exist for provision and purchase of services (the "well developed" two).

Table 3.1

COMMON RATIONALES RELEVANT TO FUNCTIONAL MECHANISMS

Rationales	Direct Service Provision	Purchase of Services Through State and Local Agencies	Regulate Service Providers	Investment in Means of Producing Services	Research Development and Dissemination of Information
Redistribute resources					
Increase net productivity	M	M	M	M	L
Increase equity	M	H	H	H	L
Fill unmet needs, accommodation	L	H	H	H	L
Economies of scale/critical mass	H	-	L	H	H
Internalized externalities					
Total population benefits	L	L	-	H	H
Visibility	L	L	-	L	L
Control and responsiveness					
Quality control	-	-	H	L	-
Fair provision	L	M	M	M	L
Level of responsibility	L	-	M	M	H
Innovation: stimulation/diffusion	-	H	-	H	H

NOTE: Degree of relevance: H equals high, M equals medium, L equals low.

THE POLICY PROCESS

A final way of visualizing the handicapped youth service system is to consider a general sequence of events through which its policies and programs flow from earliest initiation through ultimate termination.³⁵ This short subsection defines the policy process in a useful but not particularly novel way. It is included so that we

³⁵ This process is not novel. It is basically the result of theoretical insights generated by H. D. Lasswell, most recently in his *A Pre-View of Policy Science*, Elsevier, New York, 1971, Chapter 5. Equivalent labels to those employed by Lasswell have been adopted for our more specific purposes.

may refer to steps in this process later when we describe current programs for handicapped youth, without having to stop there to define what we mean by the policy process. Describing parts of the service system in terms of this sequence of decisions has helped us understand the dynamics of the system and, in the next segment of our research, may contribute to suggestions for its improvement.³⁶

Initiation/Invention

The earliest phase of the sequence begins when a given problem is initially sensed. Once a problem is recognized, many possible means to alleviate, mitigate, or resolve it may be explored. In this early creative phase, one comes to expect that numerous ill-resolved and inappropriate "solutions" will be advanced. Indeed, as much as casting about for answers, this phase concerns sharpened redefinition of the problem. Invention refers to the fragile business of reconceptualizing a problem, laying out a range of possible solutions, and then beginning to locate potentially "best" choices within that range.

Estimation

Estimation concerns predetermining risks, costs, and benefits associated with each of the various policies or solutions that emerge from the initiation/invention phase. Calculation of the likelihoods that the various possible outcomes will occur is largely focused on empirical-scientific and projective issues, while the imputation of the desirability of those outcomes is more clearly biased toward normative concerns.³⁷ The objective of estimation is to narrow the range of plausible policy solutions, by excluding the infeasible or the truly exploitative for instance, and to order remaining options according to well defined scientific *and* normative criteria.³⁸ Resource analysis, Bayesian statistics, forecasting, model construction, and an assortment of other methodologies have evolved in response to the first requisite; market research, political opinion, and other survey techniques benefit analyses, and rarely, *a priori* social-ethical assessment have been used for the second. An interesting combination of scientific and normative perspectives is inherent in efforts to conduct systematic social experiments, an activity held to be essential by, among others, Alice Rivlin. "[Social experimentation] must be an important federal activity, if we are to achieve breakthroughs in social service delivery."³⁹

³⁶ The process concept has been applied with some success in at least two specific instances to understand why large-scale and complex systems were not performing adequately. See Martin Skubik and G. D. Brewer, *Models, Simulations and Games: A Survey*, The Rand Corporation, R-1060-ARPA/RC, May 1972; and G. D. Brewer, *Politicians, Bureaucrats and the Consultant: A Critique of Urban Problem Solving*, Basic Books, New York, 1973.

³⁷ See Philip Morse and G. E. Kimball, *Methods of Operational Research*, John Wiley, New York, 1950, for a fuller explanation of these important differences.

³⁸ A typical pitfall in the process is failure to examine a range of diverse interpretations, rationales, orderings, and calculations. This requirement is obvious, but in practice cannot be stressed enough.

³⁹ Alice Rivlin, *Systematic Thinking for Social Action*, The Brookings Institution, Washington, D.C., 1971, p. 120.

Selection

Ultimately, someone must select one or a few of the "invented" and "estimated" options, and that considerable task has traditionally been the responsibility and province of policymakers, however that role is characterized.⁴⁰ Narrowly circumscribed analysts seldom confront the problem of striking a balance between the rational calculations done during the estimation phase and the multiple, changing, and conflicting goals operating throughout the entire sequence. It is a problem, among others, that is ultimately resolved by the politician, who

has to balance the myriad forces as he sees best, and the citizens judge him only to a limited extent by his accordance with their preconceived ideas. Rather, a great political leader is judged like a great composer; one looks to see what he has created.⁴¹

And that brings us to implementation, the means for carrying out selected policies.

Implementation

Implementation refers to executing a selected option according to a plan. As witnessed by heightened interest and statements of concern about failures of public policy implementation,⁴² however, it is a phase of the overall decision sequence that is little understood, not particularly appreciated, and not well developed, or as one distinguished group recently summarized it:⁴³

We became increasingly bothered in the late 1960s by those aspects of the exercise of government authority bound up with implementation. Results achieved by the programs of that decade were widely recognized as inadequate. One clear source of failure emerged: political and bureaucratic aspects of the implementation process were, in great measure, left outside both the considerations of participants of government and the calculations of formal policy analysts who assisted them. Acting through governmental organizations existing in the midst of political cross-pressures is a necessary feature of modern public affairs. The art has been but little developed.

It has become clear that to assess government performance, one must understand the implementation mechanisms operating to generate that performance, and one recommended approach has been to consider the incentive systems underlying individual, collective, and institutional behavior.⁴⁴ Improving governmental per-

⁴⁰ Bernard Crick, *In Defense of Politics*, Penguin, Baltimore, 1964 (rev. ed.), captures the essence of selection. "So many problems are only resolvable politically that the politician has a special right to be defended against the pride of the engineer or the arrogance of the technologist. Let the cobbler stick to his last. We have a desperate need for good shoes—and too many bad dreams," p. 110.

⁴¹ W. A. Lewis, "Planning Public Expenditures," in M. F. Millikan (ed.), *National Economic Planning*, National Bureau of Economic Research, New York, 1967, pp. 201-227, quote at p. 207.

⁴² Charles Schultze, *The Politics and Economics of Public Spending*, The Brookings Institution, Washington, D.C., 1968, pp. 104-105.

⁴³ The Research Seminar on Bureaucracy, Politics, and Policy, *A Report on Studies of Implementation in the Public Sector*, Harvard University, The John F. Kennedy School of Government, Cambridge, Massachusetts, March 1973, p. 1.

⁴⁴ J. S. Berke and M. W. Kirst, *Federal Aid to Education: Who Benefits, Who Governs*, D. C. Heath, Lexington, Massachusetts, 1972.

formance may depend on redesigning those underlying systems of incentives, if one concurs with Charles Schultze's observations:⁴⁵

[The failure of federal programs is] positive failure—the failure to build into federal programs a positive set of incentives to channel the activities of decentralized administrators and program operators toward the program objectives.

Evaluation

Initiation/invention and estimation are primarily forward-looking, anticipatory activities. Selection stresses the urgency of the present. Evaluation is backward-looking, concerned with inquiries about system performance and individual responsibility. Typical topics and questions that are reflected in the idea of evaluation include the following: What officials and what policies and programs were successful or unsuccessful? How can that performance be assessed and measured? Were any criteria established to make those measurements? Who did the assessment, and what were his purposes? To what ends was the valuation directed, and were they accomplished?

Evaluation is a necessary phase in the decision sequence, but the incidence of comprehensive and competent efforts in a wide variety of places is not great.⁴⁶ Institutionalization of evaluation can be either internalized (in-house) or externalized (such as by an auditing firm, a consultant, or an inspector general).⁴⁷ Evaluation is, or should be, a necessary input to the next and final phase of the decision sequence.

Termination

Termination refers to the adjustment of policies and programs that have become dysfunctional, redundant, outmoded, unnecessary, and so forth. From the conceptual and intellectual points of view, it is not a well developed phase, but one whose importance in current affairs must not be underrated. How, for instance, can a policy be rationally adjusted or terminated without its having had a thorough evaluative assessment? Who will suffer from the termination? What provisions of redress have to be considered? What are the costs involved to the individuals affected by the termination? Can they be met from other sources? What might be learned in the termination process that will inform the initiation and invention of new policies or programs in the same or related fields? The list of questions is long indeed,⁴⁸ but ignoring them or ignoring the fact that termination is linked intimately to the other steps in the decision sequence is both unnecessary and undesirable.

⁴⁵ Schultze.

⁴⁶ H. D. Lasswell, "Towards a Continuing Appraisal of the Impact of Law on Society," *Rutgers Law Review*, Vol. 21, No. 4, Summer 1967, pp. 645-677.

⁴⁷ The literature on the subject is not large, but it is growing rapidly. For an overview see F. G. Caro (ed.), *Readings in Evaluation Research*, Russell Sage Foundation, New York, 1971; and E. A. Suchman, *Evaluative Research*, Russell Sage Foundation, New York, 1967, Chapters 1-2, 4-7, and 10.

⁴⁸ Insights may be gleaned from the legal profession in which termination is an established part of contract law. Such expertise does not yet exist in other specialized fields.

4. THE ISSUE OF GOALS AND SYSTEM PERFORMANCE

To understand a system's purpose, one needs to understand its operating goals¹: Where is the system heading? To measure its performance, one needs criteria²: Has the system arrived where it was meant to go, and if not, how far off the mark is it?

As we surveyed the myriad goals or 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 which made some of the stated goals somewhat less than useful in the practical selection and operation of programs.

To specify evaluation criteria for handicapped youth (or other) programs, one must consider the goals of the overall system of services from several points of view, including those of *the affected population*, those of *officials responsible for formulating and executing individual policies and programs*, and those of *society as a whole*.³ Multiple, conflicting points of view surely will exist. It is less obvious, but nonetheless important, that programmatic evaluations should be likewise based on multiple performance criteria.

¹ Goals are categories of preferred events, whether events desired in themselves and events desired because they are instrumental, e.g., health is desired in itself and is preferred to illness, and productive employment is desired as an instrumental event and is preferred to mass unemployment. See Daniel Lerner and H. D. Lasswell (eds.), *The Policy Sciences*, Stanford University Press, Stanford, California, 1951, pp. 9-10.

² As defined here, value refers to the worth or utility of an event rather than to the measures or criteria on whose scale such valuation is made. Furthermore, values and criteria can be distinguished from norms, which are rules governing behavior. Once criteria are established, the valuation of events on those criteria provides the grounds for rejecting or accepting particular norms as undesirable or desirable. In practice the major point is that values influence decisions in the selection of possible goal events to be considered (a program's "menu" of potential goals), and in the preference ordering of these goals. See "Concept of Value," *International Encyclopedia of the Social Sciences*, Macmillan, The Free Press, New York, 1968; and K. E. Boulding, "The Ethics of Rational Choice," *Management Science*, Vol. 12, February 1966, pp. 161-169.

³ For a discussion of ways in which goal values are determined and justified, see, for example, Abraham Kaplan, *American Ethics and Public Policy*, Oxford University Press, New York, 1963; see also C. E. Lindblom, "The Handling of Norms in Policy Analysis," in Abramovitz et al., *The Allocation of Economic Resources: Essays in Honor of Bernard Francis Haley*, Stanford University Press, Stanford, California, 1959, pp. 160-179.

GOALS AS A MULTI-FACETED PROBLEM

Let us first consider goals of *the affected population*. From discussions we have had with sensorially handicapped people, we surmise that if they were to set program service goals, such goals would be of the "greatest good for the greatest number" nature and would include concepts such as

- Assurances 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 functional capability consistent with his physical or mental impairment.

This position is mediated somewhat in actuality. The objective of some members of this class of individuals would not necessarily be for the government to meet every need and to develop every potential of each handicapped person, but rather that *somehow* those needs must be met and the potential realized. This mediation of goal can occur because many of the handicapped simultaneously want to be as self-sufficient and self-reliant as possible.⁴ Attaining the greatest good for the greatest number *and* developing social and economic independence for each handicapped person are in this case complementary and supportive goals. In fact, these goals have only been attainable for selected individuals because serving all handicapped persons has required 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.

The goals of *officials responsible for formulating and executing individual policies and programs* are reflected in the services offered within particular programs designed to implement broad policy pronouncements. For example, one purpose of the Federal Vocational Rehabilitation Act is "... assisting States in rehabilitating handicapped individuals so that they may prepare for and engage in gainful employment to the extent of their capabilities..." Subsequent sections discuss how these broad types of statements have been translated into actions for each pertinent class of services currently delivered to the handicapped population. Generally, service program goals may be consistent with the goals of an *individual* handicapped person but typically do not promise to meet the needs and develop the potentials of *all* handicapped persons. Furthermore, the phrase, "subject to budget constraints," is the key implicit or explicit qualification of nearly every service program objective. We consider this constraint directly for each class of service.

The goals of *society as a whole* are fundamentally a collective ethical problem and hence not easily determined. One might hazard a guess as to what they are by considering governmental actions over a whole range of programs for the handicapped. Congress, the Office of the President, and the Department of Health, Education and Welfare have responsibilities so broad that all in a sense represent society's goals by the actions actually taken; but having made this global observation, the

⁴ At the root of this discussion is a basic concern for the quality of life led by the handicapped person; it is a very difficult question, and one that we will consider in greater detail in our second report. For a good introduction to the scientific problems associated with the concept, see N. C. Dalkey, Ralph Lewis, and David Snyder, *Measurement and Analysis of the Quality of Life*, The Rand Corporation, RM-6228-DOT, August 1970, pp. 1-40.

analyst does not have much solid information to guide his detailed evaluation efforts. Certainly these overall societal objectives share humanitarian aspects and resource constraints with the objectives of the handicapped population and those providing individual service programs. But unique and conflicting aspects of the actual goals tend to predominate, thereby making the determination of "Society's" valuation of goal events nearly impossible.

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

- Minimize current public expenditures—which implies low emphasis on 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 treatment and welfare.
- Maximize services provided primarily to the severely handicapped and the poor—which implies a conscious discrimination against the mildly handicapped and the non-poor.
- Maximize services for the mildly handicapped to achieve greater effectiveness per dollar expended—which implies discrimination of another extreme.
- Maximize the number of people served for a given fixed budget—which implies that those having relatively greater needs will not be served.
- Minimize costs for a specified number of people—which violates several desirable objectives in obvious ways.

Other extreme possibilities may be described to indicate the basic dilemma of trying to determine societal, aggregate objectives with respect to the overall handicapped population or to the individuals comprising it. In addition there is a serious problem with the relevant time frames and perspectives operating for various participants. "The person or group with a time orientation toward the present [e.g., politicians] will have difficulty in seeing the value of inoculations against disease, a future occurrence."⁵ But, in contrast, the handicapped individual's orientation may span his lifetime.

To begin working our way out of this thicket, we have concentrated on the stated objectives of individuals responsible for formulating and executing specific policies and programs and, for our immediate purposes, this has meant considering President Nixon's recent public statements on the matter and carefully reviewing former Secretary of Health, Education and Welfare, Elliott Richardson's various public positions and adopted policies.

FEDERAL GOALS

Accounting for public positions and related policies is an important activity, for as Geoffrey Vickers points out, "When we open our eyes to the scene around us, we find goals already set. Policies are being implemented, institutions are in action with

⁵ S. H. King, *Perceptions of Illness and Medical Practice*, Russell Sage Foundation, New York, 1962, p. 53.

all the historical momentum of buildings and establishments. Men are in mid-career. Budgets, even budget headings, have acquired prescriptive rights . . ."⁶

The basic thrust of many of these extant events may be summarized in current trends: to increase the comprehensiveness of Federal activities to insure integrated rather than fragmented service; to increase participation possibilities in formulating policies and programs; to improve accountability procedures; to be aware of unintended consequences of individual policies and programs; to improve the structuring and functioning of service-providing institutions; and to reduce personal dependency on the government at all levels.

The concepts behind the trends were generally laid out in President Nixon's recent message on human resources in terms of "Four Principles," which may be summarized as follows:⁷

- Increase individual freedom of choice through government initiatives to give individuals a better opportunity in life.
- Supply incentives and opportunities instead of providing services directly.
- "Rather than stifling initiatives by trying to direct everything from Washington, Federal efforts should encourage state and local governments to make those decisions and supply those services for which their closeness to the people best qualifies them."
- Insure strict fiscal responsibility to avoid inflation, recession, or tax increases.

While these are suitable general statements of objectives, they do not go far enough in their detail or extent of coverage to give more than global insights into how programs should be structured.

A key specific source of insights into the actual, operating Federal goals is contained in Elliott Richardson's remarkable report, "Responsibility and Responsiveness (II)," *Report on the HEW Potential for the Seventies*, January 18, 1973. It is remarkable in the sense that operating goals are clearly and concisely articulated as are the policy changes needed to attain these goals.

- *Increasing comprehensiveness*: "In planning and programming, our perspective must be comprehensive. . . . Integration must replace fragmentation." And, the scope of HEW must expand, "In the conceptual direction of the President's proposed Department of Human Resources, a direction of still greater comprehensiveness." (p. 10)
- *Increasing participation*: ". . . the effective management of HEW is crucially dependent upon: . . . the processes which define the relationships among people—the means openly and equitably to ensure the orderly and timely participation in the decisionmaking process by all affected parties . . ." (p. 13)
- *Increasing accountability*: (Improving HEW management means) establishing and improving "clear and fair accountability." (p. 13)
- *Increased awareness of (un)intended consequences*: One presumes that this refers to the sensing of externalities, both positive and negative—disseminating and promoting the former and redressing and eliminating the latter. (Improving

⁶ Sir Geoffrey Vickers, "Who Sets the Goals of Public Health?" *The Lancet*, Vol. 1, March 1958, pp. 599f.

⁷ As reported in *Education Daily*, Vol. 6, No. 42, March 2, 1973, pp. 1-2.

HEW management means developing) "informed and sensitive appreciation of the consequence of intended actions." (p. 13)

- *Institutional reform*: "... institutional reform can ... contribute to the conservation of limited resources. It can seek to assure that the agencies, organizations, and skills that are capable of making some contribution to the protection and development of human resources are properly deployed." (p. 21)
- *Foster non-dependency*: "... the non-dependency goal would suggest that our objectives should be: 1. To create preventive mechanisms which identify the likelihood of people sliding down the scale of personal freedom of choice and reliance on others, and which remove the dangers that threaten the status of those people. 2. To create the conditions necessary to achieve earning capacity, self-care, and personal freedom of choice. 3. To assist those who are not self-supporting to progress to the highest position on the scale that is within their capability. And 4. To ensure the adequacy of income and services, qualitatively as well as quantitatively, and the preservation of human dignity, for those who are unable to progress up the scale."⁸

Because the "non-dependency" rubric subsumes so many more specific goals, it is worth reflecting on what it might mean for policymaking, institutional structure, and service provision. Specifically, what does it imply for clarifying objectives sufficiently well that more pointed evaluations of effectiveness might be carried out?⁹

One way of translating the non-dependency concept into operational terms would be to list succinctly a broad range of objectives potentially implied or embedded in the concept. These might take the following form:

- Assurance that the needs of each handicapped person are met, and that each has the opportunity to develop to his maximum vocational and social potential.
- Effective provision of individual services that foster independence subject to budget constraints.
- Effective provision of closely related "packages" of services that foster independence, also subject to budget constraints.
- Minimization of current direct costs of providing services, subject to service obligation constraints.
- Minimization of total costs of providing services over the entire lifetimes of members of the handicapped population, subject to service obligation constraints.

It is important to distinguish between the ideas of *equity* and *adequacy*. Equity refers to social choices that distribute service fairly to the population. Increasing equity with a fixed level of resources implies providing lower levels of service to

⁸ Secretary of Health, Education and Welfare, "Planning Guidance Memorandum—1972," February 15, 1972.

⁹ An important issue associated with the concept of "non-dependency" centers on the immutable fact that a proportion of the handicapped will never achieve anything like "normal" levels of non-dependence, indeed the permanent dependence of the severely handicapped is not to be treated casually. Leslie Gardner has treated this matter forthrightly. "[In the case of the severely handicapped] why continue to press for independence: would it not be preferable to accept severe disability gracefully and to come to terms with the inferior status (by current standards) and to work towards ... 'planned dependence'? In short, should we not educate for independence—indeed for inferior status—although this is against the grain of present-day ideas of citizenship for all, with its emphasis on work for gain?" Leslie Gardner, "Planning for Planned Dependence?" *Special Education*, Vol. 58, March 1969, pp. 27-30, at p. 28.

greater numbers of the population. Adequacy refers to the availability of enough service to meet the need; i.e., what portion of those in need receive quality services?

If the main concern is equity of service delivery, this implies certain functional emphases in the areas of research, development, demonstrations, and experiments to improve knowledge and to increase productivity which, in turn, make services available to more individuals at less cost. It also implies that we must create more comprehensive, responsive, and reliable statistical systems and a more geographically disaggregated service system to insure that the services are fairly distributed. It also means that provisions for planning and managing the services must be improved.

If service delivery is considered inadequate, then the problem is in some ways harder. Its resolution implies that attention should be focused on research and development to create services and "solutions" where none presently exist, and it furthermore implies that the level of service resources must be increased.

CONTRADICTIONS AND OTHER PROBLEMS

There are at least five stated or observable contradictions in the objectives of the system serving handicapped youth. In addition, there are several related, primarily technical problems that do not appear to be easily resolved but that impede the realization of most of these objectives.

There is no national policy for handicapped children and youth. A large portion of the operational problem apparently occurs because there are basic contradictions embedded in the objectives established for institutional elements comprising the service delivery system.

There are very few service programs that benefit handicapped children and youth that are the *primary* responsibility of an operational agency. Programs serving handicapped youth exist literally everywhere in the Federal Government, but hardly anywhere are these programs the main order of business.

The objective of increased participation in decisionmaking in fact does not appear to be realized. Someone must select a single choice from the array of those presented for a policymaker's attention, and this process inevitably results in a forced choice when resources are limited but demands on the resources are not. Resource choices are always being made, but with a prime operational goal being a reduction in the overall Federal budget, apparently the number of persons participating in the allocation of that budget has not increased.

There is a contradiction between the increasing insistence on individual freedom and the parallel trend toward ever more complex forms of social intervention.¹⁰

The objective of insuring equality of opportunity does not seem to be realized with respect to the handicapped, any more than it does for other disadvantaged groups in our society.¹¹

¹⁰ This is a major theme in Gunnar Myrdal, *Beyond the Welfare State*, Yale University Press, New Haven, Connecticut, 1959, pp. 99-102. It is considered in some detail in Jerald Hage and Michael Aiken, "Relationship of Centralization to other Structural Properties," *Administrative Science Quarterly*, Vol. 2, 1967, pp. 72-92.

¹¹ The matter is not novel and has in fact been the source of unending reports, studies, books, and entreaties. See D. C. Marsh, *The Future of the Welfare State*, Penguin, Baltimore, 1964, for an overall

Not only are there fundamental contradictions evident in some of the very global objectives posited for handicapped individuals, but there are naturally resultant problems in measuring progress toward those relatively general objectives.

It is safe to say that we require multiple measures and criteria for assessing system objectives. We need them to avoid cheating, suboptimization, and efforts to "beat the system."¹² More importantly, we need basic information before those multiple measures may even be utilized.¹³

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 point into account. We have developed four dimensions and have created criteria to measure programs on each of them: (1) effects on the individual handicapped person, (2) future economic effects, (3) current resource consumption, and (4) equity. These dimensions permit one to make comparative judgments from several viewpoints without getting bogged down in arguments over which objective is "best."¹⁴ In fact, it is quite conceivable that similar policy recommendations might flow from analyses using different objectives, i.e., the so-called "dominant choice." Our subsequent report will present data on a spectrum of criteria described in Sec. 11, and the reader may assign his own weights to each criterion to suit his own objectives.

These are hard matters to understand and resolve. At a minimum, one should be made aware of what it means to pursue each of the stated objectives to something like its logical conclusion before deciding definitely on a particular allocation of resources. It may very well turn out that the objective may not be attainable or it may cost a great deal in terms of other, more feasible objectives foregone in the bargain.

view; and see J. S. Coleman et al., *Equality of Educational Opportunity*, U.S. Department of Health, Education and Welfare, Office of Education, 1966, for a more detailed and well known statement.

¹² Alice Rivlin has spoken about these practices with notable frankness in *Systematic Thinking for Social Action*, The Brookings Institution, Washington, D.C., 1971, pp. 126-130.

¹³ On the information deficiency problem, see E. B. Sheldon and W. E. Moore (eds.), *Indicators of Social Change: Concepts and Measurements*, Russell Sage Foundation, New York, 1968; Mancur Olson, *Toward a Social Report*, U.S. Department of Health, Education and Welfare, 1969; and Daniel Bell, "A Social Report in Practice," *The Public Interest*, No. 15, Spring 1969, pp. 98-105, where this essential statement concludes the paper: "The nation must decide which objectives should have the higher priorities, and choose the most efficient programs for attaining these objectives. Social reporting cannot make the hard choices the nation must make any easier, but ultimately it can help to ensure that they are not made in ignorance of the nation's needs." P. 105.

¹⁴ Two standard works detail what is involved in this issue: S. B. Chase (ed.), *Problems in Public Expenditure Analysis*, The Brookings Institution, Washington, D.C., 1968; and Robert Dorfman (ed.), *Measuring Benefits of Government Investments*, The Brookings Institution, Washington, D.C., 1965.

PART 2

CURRENT SERVICE POLICY

This part of the report presents current policy, programs, and problems of service to handicapped youth by major types of agencies in the system, with a section devoted to each one: vocational services, education, welfare, health, health research, and mental health and retardation. The beginning of each section presents a short overview for all programs within the generic type of agency.

5. VOCATIONAL SERVICES TO HANDICAPPED YOUTH

This section first summarizes Federal and state programs of vocational services to handicapped youth. Next, a detailed description of the Federal role and program objectives is presented, followed by information on handicapped youth served by the vocational rehabilitation (VR) agencies. Then, employment services provided by other agencies and a survey of the state vocational rehabilitation agencies are described.

OVERVIEW AND SUMMARY

Vocational rehabilitation and employment programs in the United States are designed to return physically and mentally handicapped persons to gainful employment, which may include family work, sheltered employment, or gainful homebound work. In 1970, the programs assisted over 100,000 physically or mentally handicapped youth under age 22. The Vocational Rehabilitation program provided a comprehensive set of services through state agencies for 101,000 handicapped youth whose cases were closed in 1970. Seventy-seven percent of those youth accepted for vocational rehabilitation services were rehabilitated. The total expenditure for VR and other employment services for youth in FY 1972 was an estimated \$202,254,000, of which Federal and state shares were 83 and 17 percent, respectively.

Table 5.1 shows a breakdown of the expenditures for the three major programs: Vocational Rehabilitation, the Committee on Employment for the Handicapped, and Employment Services. Over 75 percent of the expenditures are for the basic State-Federal Vocational Rehabilitation Program that provides a wide variety of services to individuals through state agencies. Data shown in Table 5.2 indicate that the most prevalent types of handicapped youth given vocational services are those with mental retardation (29,654 or 29 percent), mental illness (24,032 or 24 percent),

orthopedic impairments or absence of extremities (16,465 or 16 percent), and other health impairments such as cardiac, respiratory, and digestive disorders (15,987 or 16 percent).

Federal involvement in civilian vocational rehabilitation began in 1920 with a 50:50 matching grant program to states to provide vocational training, counseling, prosthetics and placement services to physically handicapped persons. Since then, the Federal role has expanded markedly so that now the Federal Government funds 80 percent of the basic VR program; supports service to all types of physically or mentally disabled persons with a substantial handicap to employment but with "high" vocational potential; allows provision of virtually any service that a client might need; supports research, the construction of physical plants, and the training

Table 5.1
SUMMARY OF ESTIMATED TOTAL EXPENDITURES ON VOCATIONAL
SERVICES TO YOUTH AGED 0-21, FY 1972

Federal Expenditures	
Federal administration of VR services	\$ 1,705,000
VR research and demonstration	6,700,000
Training VR personnel	6,925,000
Construction and improvement of VR facilities (1971) ...	9,820,000
Grants to states for basic VR program ^a	124,943,000
Special VR service projects	13,900,000
Presidential Committee on Employment for Handicapped ...	152,000
Employment services	3,750,000
Total	\$167,895,000
State Expenditures	
Construction and improvement of VR facilities (1971) ...	\$ 2,264,000
Basic VR program (1971)	31,759,000
Special VR service projects	336,000
Total	\$ 34,359,000
Total Federal and State Expenditures	\$202,254,000

SOURCE: See subsection, "Current Vocational Rehabilitation Programs," in this section for data sources and estimation methods.

^aExclusive of funds for construction and improvement of VR facilities.

of professional personnel; and gives special attention to the needs of low-incidence population groups. Step by step, the evolution of Federal assistance in VR can be interpreted as one of perceiving the unmet needs of disabled persons, and providing otherwise unavailable funds to help meet those needs.

Although the Federal Government provides the greatest share of funding for VR programs, the state role is also a major one because states operate the VR

Table 5.2
SUMMARY OF VOCATIONAL REHABILITATION OF YOUTH, BY DISABILITY GROUP

Handicap Group	Number Accepted for Service, FY 1970 Closures	Number Successfully Rehabilitated, FY 1970	Number Rehabilitated as Percent of Number Accepted, FY 1970 Closures	Percent of Basic Program Expenditures on Handicap Group, FY 1970	Approximate Total State and Federal Expenditures on Handicap Group, FY 1972 ^a
Blind	332	249	77	1.2	\$ 2,427,000
Partially sighted	1,235	964	78	3.3	6,674,000
Other visual impairments	5,197	4,443	85	5.7	11,528,000
Deaf, unable to talk	1,145	900	79	1.5	3,034,000
Deaf, able to talk	1,267	1,081	85	1.7	3,438,000
Hard-of-hearing	1,931	1,672	87	2.3	4,450,000
Orthopedic impairments or absence of extremities	16,465	13,520	82	23.7	47,934,000
Mental illness	24,032	15,974	67	16.5	33,372,000
Mental retardation	29,654	22,862	77	23.7	47,934,000
Other health impairments	15,987	13,249	83	16.7	33,776,000
Speech impairments	1,608	1,378	86	1.9	3,843,000
Other impairments	2,172	1,524	70	2.0	4,043,000
Total	101,015	77,816	77	100.0 ^b	\$202,254,000 ^b

SOURCE: See subsection, "Current Vocational Rehabilitation Programs," in this section for data sources.

^a Assumes total FY 1972 expenditures are distributed across handicaps in the same proportions as the FY 1970 Basic VR program expenditures were.

^b Columns do not total exactly due to rounding.

agencies, subject to Federal guidelines. And state personnel directly provide certain services such as counseling and placement, but contract with vendors for other services such as medical and occupational training.

Since available detailed statistics on the VR program were not disaggregated by client age, it was necessary for us to analyze data from individual client reports (DHEW Form RSA-300—Case Service Reports). The following summary data were compiled at The Rand Corporation for age 0-21 clients and referrals whose cases were closed in FY 1970. The states had 184,068 youth referrals, of which 55 percent were accepted for service, and 77 percent of these were rehabilitated. Nearly all young clients were between 14 and 21, nearly two-thirds were male, four-fifths were white, and the median grade completed was 11. The majority of applicants were supported by their family or friends, and only 9 percent received public assistance.

The largest single source of referrals to the program was the school system; only 15 percent were not referred by someone connected with a public or private service agency. Only 5 percent of those not accepted were reportedly referred elsewhere by VR personnel. The number of successful rehabilitations per 100,000 general population aged 14-21 averaged 260 but ranged from less than 100 in some states to over 500 in others. Referrals accepted varied across states, from 46 to 70 percent, as did the success rate for those accepted, from 46 percent in one state to 90 percent in another. The relative emphasis on different types of handicaps also varied considerably across the states.

Of youth referred for VR services, only 11 percent were rejected as unqualified to receive service. The most frequent reasons for not accepting youth were that they refused service; or were unable to be located or contacted or had moved; or failed to cooperate. Of reasons that youth accepted into the program were not rehabilitated, the most prevalent were that they could not be located, contacted or had moved.

For successful clients, only 11 percent were working during the week preceding referral. Average weekly earnings at closure were \$76. The estimated annualized earnings of all rehabilitated youth rose from \$20,637,000 at referral to \$279,851,000 at closure. A subsequent Rand report will analyze in depth the costs and benefits of this program.

The average times from referral to acceptance and closure were 6 and 21 months, respectively. Three-quarters of the rehabilitated youth received job training, one-third received physical or mental restorative services, slightly less than one-third received income assistance, and one-third received other services.

Total expenditures averaged \$1300 per person served, or \$1687 per person rehabilitated. The average total expenditures per youth rehabilitated varied across the states from \$800 to \$4500. Expenditures by type of handicap varied from \$1356 per mentally ill youth vocationally rehabilitated to \$6514 per blind youth rehabilitated.

In addition to the basic VR program, there are four major vocationally-oriented programs: Committees on Employment of the Handicapped that promote employment opportunities for the physically and mentally handicapped population; a Civil Service program aimed at increased Federal employment of the handicapped; a vending stand program in government buildings for visually impaired persons; and

the Employment Service Agencies that offer counseling and job placement referrals.

In our survey of state vocational rehabilitation agencies, problems in the present system cited most often were insufficient funds; inadequate coordination among different agencies providing services to handicapped persons; tardiness and unpredictability of Federal funding levels; and the very few attempts made to reach out and locate persons needing vocational services.

In summary, we have five principal observations on vocational services for handicapped youth.

1. The program for older youth offers a very comprehensive package of services and appears generally successful in meeting the objective of gainful employment.

2. It is not surprising, but nonetheless worth emphasizing, that many authorities feel that present service funding levels are inadequate, and that more handicapped could be successfully served if budgets were increased. Funds directly supporting professional personnel training and facilities construction also are low in relation to the need.

3. VR program data are the best available for any federally supported program serving handicapped youth. The utility of the data in understanding and comparing various state programs would be increased, however, if the statistics presented were more disaggregated. More programmatic analysis of these data might also help to explain reasons for variations in success rates and other significant differences across state agencies and to identify excellent program elements that could profitably be disseminated.

4. Inequities in the level of service to the client, in the fraction of the population served, and in the different types of handicaps treated exist across states.

5. The issue of "creaming" of referrals, in which some counselors reportedly select the least handicapped (as opposed to the severely handicapped) to increase the number of successful clients, is an important one that needs further attention and investigation.

ROLES AND GOALS ¹

The Changing Federal Role in Vocational Rehabilitation

Initial Federal involvement in vocational rehabilitation occurred in 1917 with services provided to disabled World War I veterans. Civilian disabled were first

¹ Historical information in this section is compiled from the following sources: U.S. Congress, Senate, Committee on Labor and Public Welfare, *Rehabilitation Act of 1972*, 92^d Cong., 2d sess., S. Report 92-1135, September 20, 1972; U.S. Department of Health, Education and Welfare, *An Introduction to the Vocational Rehabilitation Process*, Vocational Rehabilitation Administration, Report 68-32, July 1967; U.S. Department of Health, Education and Welfare, *Statistical History: Federal-State Program of Vocational Rehabilitation, 1920-1969*, Rehabilitation Services Administration Report, June 1970; U.S. Department of Health, Education and Welfare, *Caseload Statistics: State Vocational Rehabilitation Agencies: 1971*, Social and Rehabilitation Service, DHEW Publication No. (SRS) 72-25401, December 1971; and U.S. Department of Health, Education and Welfare, *State Vocational Rehabilitation Agency: Program Data, FY 1971*, Social and Rehabilitation Service, DHEW Publication No. (SRS) 72-25016, March 1972.

included in 1920 under the Smith-Fess Act, which provided Federal grant-in-aid programs to states for vocational training, counseling, prosthetics, and placement services for physically handicapped persons. States received funds according to population on a 50:50 matching basis. Preferential employment opportunities were given to blind persons in 1936 when the Randolph-Sheppard Act permitted licensing of vending stands to them in Federal buildings or federally sponsored buildings.

The Federal role increased significantly in 1943: (1) to include persons who were mentally ill or mentally retarded; (2) to accept separate state agencies for the visually handicapped into the program; and (3) to provide "any services necessary to render a disabled individual fit to engage in a remunerative occupation."² Under (3), the most significant new provisions included were medical, surgical, and other physical restoration services.

In 1954,³ the Federal role was again expanded. Besides helping states pay for VR services to disabled persons, the Federal Government would help train service personnel, alter or expand rehabilitation facilities and workshops, and extend rehabilitation knowledge through research and demonstration grants. The financing provisions were also modified so that both the state's population and its per capita income were considered in the allocation formula. The Federal share varied from 50 to 70 percent, and averaged about 60 percent of the total of Federal plus state expenditures. Federal funding of up to 75 percent was made available to encourage state program improvement and extension to disability groups and geographic locales not being adequately served.

The Vocational Rehabilitation Act Amendments of 1965 increased the Federal share of funding to 75 percent; allowed a person to receive services for a short time (up to 18 months in some cases) while his employment potential was evaluated; prohibited states from using economic-need tests in deciding whether to give diagnostic, counseling, and placement services; provided funds for constructing *new* facilities and workshops; and extended from 2 to 4 years the length of time a person could receive professional training assistance.

In 1967, provision was made for a National Center for Deaf-Blind Youth and Adults; and services were extended to migratory agricultural workers. Services were expanded to include follow-up after placement, and families of disabled persons could be served under the 1968 Amendments.⁴ In addition, the Federal share of funding increased to 80 percent in 1968. A major amendment passed, but has never been funded, that allows for vocational evaluation and work adjustment services to persons who are disadvantaged (but not necessarily physically or mentally disabled) "by reason of their youth or advanced age, low educational attainments, ethnic or cultural factors, prison or delinquency records, or other conditions that constitute a barrier to employment."⁵

In summary, the present Federal role in vocational rehabilitation is a dominant one and has expanded in five dimensions over the last 50 years:

- The Federal Government provides 80 percent of the Federal-state total funding.
- It supports service to all types of physically or mentally disabled individuals

² P.L. 78-113, *1943 Amendments to Social Security Act of 1935*.

³ P.L. 83-565, *1954 Amendments to Social Security Act of 1935*.

⁴ P.L. 90-341, *1968 Amendments to Vocational Rehabilitation Act*.

⁵ Section 15 of *Vocational Rehabilitation Act*, as amended.

with a substantial handicap to employment but with "high" vocational potential (i.e., in practice as of 1972, it does not include the most severely disabled).

- It allows the provision of virtually any service that a client might need.
- It makes funds available for research, demonstration projects, physical plant construction, and service personnel training.
- It gives special attention to the needs of low-incidence population groups, such as the deaf-blind, which might not be effectively met on a state basis.

The Federal rehabilitation role at present does not include

- Service to physically or mentally disabled persons who have very low vocational success potential.
- Direct provision of services to individuals.
- Outreach programs that attempt to locate all disabled persons who might benefit from vocational rehabilitation services.

Viewed over the half century, the Federal role seems to have been consistently updated to better insure disabled persons a "right to work." Step by step, its role can be interpreted as one of perceiving the unmet needs of disabled persons, and providing otherwise unavailable funds to help meet those needs by closing gaps in types of services offered to help achieve vocational success; gaps in types of disability served; and gaps in R&D, facilities, and service personnel.

In addition to the VR program, the Federal Government is active in promoting employment of the handicapped through the Presidential Committee on Employment of the Handicapped, Civil Service Commission efforts to place handicapped persons in Federal Government jobs, and funding of state Employment Service Agencies.

Proposed Rehabilitation Act of 1972⁶

The Act that Congress passed but that the President vetoed in late 1972 and again in early 1973 provided for continuing, revising, and expanding the existing vocational rehabilitation program. One prime revision earmarked 15 percent of all appropriations for the basic program as supplementary funds to increase services to the severely handicapped. In addition, the proposed legislation would have substantially enlarged program goals by removing the restriction that the rehabilitation be strictly vocationally oriented. This would have significantly changed the group of people eligible for services. The proposed Act stipulated that up to 10 percent of the service funds could be spent on severely handicapped persons to enable them to live and function more independently and self-sufficiently even if a realistic vocational goal could not be established. However, rehabilitation funds could not be expended on handicapped persons without vocational potential until maximum effort was made to obtain full or partial funding for needed services from other Federal, state, and local service programs.

Under this Act, the VR program would also have provided for special categorical funds for Centers for Spinal Cord Injury, Centers for Low Achieving Deaf in-

⁶ U.S. Senate Report 92-1135.

dividuals, services to deaf-blind and older blind persons, projects for migratory agricultural workers, and grants for services to persons with end-stage renal disease. The Centers for Spinal Cord Injury would be set up regionally for research, demonstration, and the direct provision of services to individuals. A few of these centers would be established to test the potential effectiveness of a nationwide network of spinal cord injury service centers. The Rehabilitation Centers for the Deaf would be for training and service improvement demonstration and would serve only those beyond school age. The single Deaf-Blind Center would develop and disseminate information on better techniques of serving that population.

Organizationally, the proposed Act would have established a mandatory "ombudsman" system in each state to seek to resolve applicant and client complaints. It would also have established an Office of the Handicapped in the Office of the Secretary of Health, Education and Welfare to plan, review, evaluate, and coordinate programs for the handicapped and to collect and disseminate information. To permit more efficient state program planning, the Act recommended advanced Federal funding.

The State Role in Vocational Rehabilitation

States operate and directly provide VR services. They contribute up to 20 percent of all funds expended, and operate within broad guidelines set up by the Federal Rehabilitation Services Administration.⁷ The state rehabilitation agencies tailor their programs within the guidelines to suit local situations. While state personnel directly provide certain services to individuals such as diagnostic evaluation, counseling, rehabilitation planning, and placement, private vendors under state contract often perform other services such as medical/surgical treatment, physical restorative and vocational training.

The State-Federal Vocational Rehabilitation Program is "designed to return physically and/or mentally handicapped persons to gainful employment and meaningful lives. . . . The (FY 1973) goal is to serve 1,195,000 disabled individuals, of which 253,000 will be public assistance recipients. . . . This 253,000 represents approximately 85 percent of the disabled public assistance recipients who could benefit from rehabilitation services under the present state of the art. . . . An estimated 326,000 individuals will be rehabilitated into gainful employment, of which 66,000 will be public assistance recipients."⁸

The program is strictly vocational, and physically or mentally handicapped persons may be provided "any goods and services necessary to render [them] fit to engage in a gainful occupation. . . ."⁹ The handicapped person served, however, must have a "substantial handicap to employment, which is of such a nature that vocational rehabilitation services may reasonably be expected to render him fit to engage in a gainful occupation, including a gainful occupation that is more consistent with his abilities and capabilities."⁹ That is, he must need the services and have reasonable

⁷ For rules and regulations, see the *Federal Register: Vocational Rehabilitation Programs and Activities*, Vol. 34, No. 200, October 1969.

⁸ U.S. Department of Health, Education and Welfare, *Justifications of Appropriation Estimates for Committee on Appropriations—FY 1973*, Vol. VI (hereafter cited as *Justifications of Appropriation Estimates*).

⁹ *Federal Register*.

potential to benefit from them. He may also be served to evaluate his rehabilitation potential. The term gainful occupation is interpreted broadly to include "employment in the competitive labor market; practice of a profession; farm or family work . . .; sheltered employment; and home industries or other gainful homebound work."⁹

Other objectives of Federal rehabilitation programs in the states include increasing the knowledge of rehabilitation techniques and their application, and increasing the supply of manpower and facilities for serving the disabled.

As far as we could determine during our interviews, the objectives used in practice are consistent with the officially stated objectives. Several people indicated, however, that rehabilitation counselors and state administrators tend to try to maximize the number of successful rehabilitations. This tendency, known as "creaming," supposedly emphasizes the acceptance and service of less severely vocationally handicapped persons and persons needing the least costly services. It also supposedly emphasizes selection of occupations in which training and placement is relatively easy. Examples of increasing the number of reported successes at low cost would be to provide a pair of eyeglasses or a hernia operation to an employed applicant and then send him back to his current job. On the whole, however, VR objectives are clearly stated and seem to be well understood and adhered to in the states.

Models, Functions, and Rationales

The Federal role in rehabilitation is best characterized in terms of our Controllorship Model, described in Sec. 3, because individual states are responsible for providing rehabilitation services under strong Federal guidelines and primarily with Federal funds.

It appears, however, that current Presidential Initiatives in revenue sharing are aimed at redefining the Federal role in domestic programs to give more authority and responsibility to states and localities. While that initiative has not been applied to vocational rehabilitation as yet, the Federal role in VR is clearly a strong one that might be lessened. If the current Federal role were to be shifted by moving toward our Model III, Special Revenue Sharing, Plus, then the Federal guidelines under which the states function would be considerably reduced in number and specificity. Such a hypothetical shift to increased state authority and responsibility, because the states currently have direct responsibility for operating the program of service to individuals, should not cause wrenching discontinuities or extensive hardships. In fact, there may be good reason *not* to select VR for the initial phases of revenue sharing on the grounds that the Federal-state balance of authority and responsibility is not currently tipped excessively to favor the Federal component and could therefore easily be left to some future date for fine-tuning and attention. Granted, there are problems with the present Model II Controllorship style of operations; e.g., it is difficult to weigh all contingencies confronting the local and state service delivery agencies from the Federal level, and it is no mean feat to devise programs that will support both the equitable and efficient delivery of services as well as Federal policy objectives to the greatest extent possible. But the VR component of the handicapped system, as compared with several other components that

we report on, appears to be functioning adequately and could be left for the time being while other, less adequate programs are given needed attention.

The Federal functions of providing research and development resources, "seed money," demonstrations, and data standardization and collection are all reasonably well developed. Twenty Special Centers and 16 Regional Research Institutes are currently fulfilling the R&D and demonstration functions in ways noted later in this section. And we were most favorably impressed by the quality and quantity of VR data that the Federal Government collected from all the states; of all the programs we considered, the VR data are the best available in allowing comprehensive program evaluations. These data allow some additional measure of control over all rehabilitation programs. The control mechanism has been indirectly stressed through the Form RSA-300 data collection procedures; comprehensive program evaluations using these data are a rather underdeveloped but potentially important phenomenon.¹⁰

The rationales most routinely used to explain the Federal rehabilitation role are the provision of otherwise unavailable resources, the needed stimulation of new devices and rehabilitation techniques, and the need for a balance wheel redressing fiscal inequities among the states in their ability to provide services.

CURRENT VOCATIONAL REHABILITATION PROGRAMS

Characteristics of the State-Federal Program in FY 1970¹¹

Statistics of the Rehabilitation Services Administration are not disaggregated in detail by client age; therefore, to obtain an accurate, in-depth picture of youth services, we conducted a computer-based analysis of data from case service reports on each individual client. That Rand analysis is the source of all data on 1970 clients under age 22 presented in the tables in this section. The latest data available for research use were for FY 1970. Since the program structure and goals did not change markedly from 1970 to 1972, these FY 1970 data should provide a reasonably accurate picture of the current program if allowance is made for increased funding levels. This subsection presents the 1970 program and client characteristics, followed by an overview of 1972 data on vocational rehabilitation, training rehabilitation personnel and construction of facilities, and research on rehabilitation.

Youth Caseload, FY 1970 Closures. Of a total of 184,068 persons aged 0-21

¹⁰ For a description of various studies that are under way or have been recently completed using the RSA-300 data, see "Previous Studies and Data Availability," subsection in this section.

¹¹ Data presented on persons under age 22 have been computed at The Rand Corporation from FY 1970 "Case Service Reports," DHEW Form RSA-300, submitted by states on each individual applicant at the time of case closure, and from a 1972 Rand Corporation Survey of state VR Agencies. Population data are from the 1970 U.S. Census of Population. Data on VR clients of all ages are drawn from the following U.S. Department of Health, Education and Welfare publications: *Caseload Statistics—State VR Agencies—1971*; *Justifications of Appropriation Estimates*; *State Vocational Rehabilitation Agency Program Data—FY 1971*; *Statistical History—Federal-State Programs of Vocational Rehabilitation, 1920-1969*; and several issues of *Statistical Notes*, Rehabilitation Services Administration publication series.

who were referred or applied for VR services in FY 1970, 101,015 (55 percent) were accepted and of these 77,816 (77 percent) were successfully rehabilitated.¹²

Table 5.3 shows caseloads and success rates by state. Note the considerable variation across states in the number of successful rehabilitations per 100,000 population aged 14-21, the relevant age range of youth in the VR program. For example, the national average is 260 per 100,000, but Oregon and California successfully serve less than 100 youth per 100,000, whereas Oklahoma and South Carolina successfully serve over 500 per 100,000. Also note that the acceptance rate varies by state from 46 percent in several states to 70 percent in Connecticut, and the success rate per youth accepted varies across states from 46 percent in Nevada to 90 percent in Indiana. Various hypotheses can be formulated to explain these differences, and testing of such hypotheses in subsequent research should yield important policy implications.

The emphasis on youth in the state programs ranges from 10 percent of rehabilitations of all ages in the 0-21 age group in Arkansas to 60 percent in Indiana. Of course, these numbers must be considered with the knowledge that some states might be serving more difficult cases on the average than others; but despite statistical difficulties, the data indicate significant differences in the programs across states. And the differences cannot all be attributed to statistical fluctuation. They suggest differences in program effectiveness as well as geographic inequity across states in the fraction of handicapped youth served.

Our analysis indicates that national summary data should be presented in enough detail by type and severity of handicapped client so that a clearer picture of each state program's successes is available. The overall total number of successfully rehabilitated clients can be very misleading and could be improved by disaggregation. In-depth studies, beyond the scope of this project, are needed to analyze the most effective state programs and to disseminate this information to states with less effective programs. Changes in program rules and regulations are one method of attempting to correct the geographic and age inequities in the proportion of youth served.

Table 5.4 shows clients by type of handicap. Although program objectives are clearly defined, handicapping conditions are not, permitting states to exercise a great deal of judgment and making comparison across states difficult. Note that mental and physical impairments each account for about half of the youth served. Mental illness and retardation each account for about one-quarter of those accepted, while orthopedic and other health impairments each account for about one-sixth of those accepted.

Looking in more detail at the client breakdown by handicap leads to interesting questions such as why, of the total accepted with some visual problems, less than one-fourth qualify as legally blind. One partial answer is that most people with some visual impairment are not legally blind; i.e., over one and one-quarter million people who are unable to read normal newspaper print even with eyeglasses are not legally blind, while the total number of legally blind persons in the United States is approximately 400,000. Another possible explanation is the creaming process mentioned earlier.

¹² That is, both the client and employer gave a favorable employment prognosis after a month on the job. Data describe FY 1970 case closures only. Thus, data such as expenditures for active cases not closed during that year are excluded; however, data on expenditures for the FY 1970 closures include expenditures incurred in previous years if the case was open prior to FY 1970.

Table 5.3

VOCATIONAL REHABILITATION YOUTH CASELOAD BY STATE, FY 1970 CLOSURES

State	Youth Aged 0-21						
	Referred	Accepted	Rehabilitated	Number Rehabilitated per 100,000 Population Aged 14-21	Rehabilitated as Percent of all Ages Rehabilitated	Accepted as Percent of Referred	Rehabilitated as Percent of Accepted
U.S. Total	184,068	101,015	77,816	260	29.5	55	77
Alabama	3,048	2,024	1,487	278	24	66	73
Alaska	371	200	105	216	29	54	53
Arizona	1,334	624	461	170	30	47	74
Arkansas	1,230	817	547	193	10	66	67
California	10,775	5,007	2,745	94	19	46	55
Colorado	2,231	1,391	1,007	286	35	62	72
Connecticut	1,976	1,377	1,079	260	41	70	78
Delaware	434	252	165	205	23	58	65
D.C.	2,359	1,210	917	825	28	51	76
Florida	9,800	4,506	3,239	355	27	46	72
Georgia	6,531	3,770	2,902	408	26	58	77
Hawaii	707	425	238	194	37	60	56
Idaho	660	342	285	252	40	52	83
Illinois	8,479	4,622	4,116	262	34	55	89
Indiana	3,397	1,764	1,591	204	60	52	90
Iowa	4,184	2,442	1,937	462	47	58	79
Kansas	1,202	777	510	148	35	65	66
Kentucky	4,045	2,408	1,992	404	23	60	83
Louisiana	4,286	2,765	2,162	364	42	65	78
Maine	712	333	247	169	36	47	74
Maryland	5,142	3,067	2,404	426	31	60	78
Massachusetts	3,825	2,070	1,630	200	39	54	79
Michigan	6,577	4,568	3,296	243	40	69	72
Minnesota	3,638	1,716	1,498	260	33	47	87
Mississippi	2,362	1,078	847	334	26	46	79
Missouri	7,025	3,248	2,473	369	38	46	76
Montana	701	375	315	292	35	53	84
Nebraska	1,349	842	652	292	46	62	77
Nevada	507	249	114	176	21	49	46
New Hampshire	386	209	143	134	33	54	68
New Jersey ^a							
New Mexico	1,041	520	303	185	38	50	58
New York	8,843	5,349	3,830	156	36	60	72
North Carolina	7,328	3,359	3,006	363	27	46	89
North Dakota	651	422	371	367	21	65	88
Ohio	7,508	4,002	3,115	197	38	53	78
Oklahoma	4,479	2,534	1,994	524	31	57	79
Oregon	1,060	622	291	93	15	59	47
Pennsylvania	15,346	7,758	5,835	351	31	51	75
Rhode Island	1,381	828	704	494	37	60	85
South Carolina	4,611	2,574	2,269	513	26	56	88
South Dakota	716	396	338	315	52	55	85
Tennessee	3,545	2,037	1,752	296	12	57	86
Texas	7,548	4,689	3,616	209	26	62	77
Utah	1,535	966	790	436	40	63	82
Vermont	332	187	134	193	28	56	72
Virginia	6,884	3,846	3,126	435	33	56	81
Washington	2,905	1,437	1,008	193	39	49	70
West Virginia	2,699	1,368	1,118	423	18	51	82
Wisconsin	5,681	3,338	2,897	434	32	59	88
Wyoming	418	232	158	311	32	56	68

^aData not available.

Table 5.4

VOCATIONAL REHABILITATION YOUTH CASELOAD BY HANDICAP GROUP, FY 1970

Handicap Group ^a	Referred		Accepted		Rehabilitated		Accepted as Percent of Referred	Rehabilitated as Percent of Accepted
	Number	Percent	Number	Percent	Number	Percent		
Blind	561	0.3	322	0.3	249	0.3	57	77
Partially sighted	1,823	1.0	1,235	1.2	964	1.2	68	78
Other visual impairments	11,377	6.1	5,197	5.1	4,443	5.7	46	85
Deaf, unable to talk	1,553	0.8	1,145	1.1	900	1.2	74	79
Deaf, able to talk	1,938	1.1	1,267	1.3	1,081	1.4	64	85
Hard of hearing	4,207	2.3	1,931	1.9	1,672	2.1	46	87
Orthopedic impairments or absence of extremities	30,358	16.5	16,465	16.3	13,520	17.4	54	82
Mental illness	45,641	24.7	24,032	23.7	15,974	20.5	53	67
Mental retardation	47,141	25.6	29,654	29.4	22,862	29.4	63	77
Other health impairments	31,492	17.1	15,987	15.8	13,249	17.0	51	83
Speech impairments	2,913	1.6	1,608	1.6	1,378	1.8	55	86
Other impairments	5,064	2.8	2,172	2.2	1,524	2.0	43	70
Total	184,068	100.0	101,015	100.0	77,816	100.0	55	77

^a Definitions of handicaps given in the U.S. Department of Health, Education and Welfare, "Statistical Reporting Procedures," *Rehabilitation Services Administration Manual*, Chapter 13, are grouped here as follows:

Blind is totally blind, no light perception (code 10).
Partially sighted is legally but not totally blind (code 11).

Other visual impairments are visual defects but not within the definition of legal blindness (codes 12, 13, 14).

Deafness, unable to talk (code 20); deafness, able to talk (code 21), and other hearing impairments (code 22) are not further defined in the RSA reporting instructions to the states.

Orthopedic impairments or absence of extremities are orthopedic deformities or functional impairments, and absence or amputation of extremities (codes 30 to 39 and 40 to 44).

Mental illness is psychotic disorders (code 50), psychoneurotic disorders (code 51) and other mental disorders (code 52).

Mental retardation is subjectively and lengthily defined as basically an IQ below 85 on an individualized test plus the presence of maladaptive behavior associated with subnormal intellectual functioning. Other health impairments include impairments related to neoplasms, allergic, endocrine system, metabolic and nutritional diseases, diseases of blood and blood-forming organs, and nervous system, cardiac, circulatory, respiratory, digestive or genito-urinary disorders (codes 60 to 67).

Speech impairments include cleft palate and harelip, speech imperfections, stammering and stuttering, laryngectomies, aphasia, and other speech impairments (code 68).

Other impairments as used here mean anything not classified in above codes plus alcoholism (code 520) and drug addiction (code 521).

Since at least two-thirds of those accepted in each handicap group are successfully rehabilitated, it appears that the states have developed fairly good methods of screening out applicants with the lowest rehabilitation potential. The applicant rejection rate is 45 percent for reasons discussed later.

Comparing the incidence of various impairments in VR clients and in the U.S. population, as estimated by the U.S. Bureau of Education for the Handicapped (BEH),¹³ is interesting but difficult to interpret because neither VR nor BEH definitions of handicapping conditions are clear, and because a physical impairment (e.g., slight speech impairment) may not constitute a significant vocational impairment. BEH estimated that 53 percent of the aged 5-19 handicapped population have a mental handicap (23 percent retarded, 20 percent emotionally disturbed, and 10 percent learning disabled), whereas about 50 percent of clients aged 14-21 under VR agency auspices have a mental impairment. The tabulation below compares BEH percentages of the total youth handicapped population and VR percentages of clients served, by various impairments. These comparisons suggest that the VR agencies are placing a relatively heavy emphasis on serving visual, orthopedic, and other health impaired youth.

Handicap	BEH	VR
Visual impairments	1.0	7.2
Hard of hearing	5.0	2.1
Deaf	0.8	2.6
Speech impairments	35.1	1.8
Crippled or other health impairments ..	5.0	34.4

Illustrative comparisons of all youths rehabilitated in FY 1970 with rehabilitations of all ages are shown below. Mental illness, exclusive of alcoholism and drug addiction, was about the same for youth as it was for clients of all ages.

Handicap	Percent of VR Rehabilitations	
	Age 0-21	All Ages
Visual impairments	7.2	8.8
Hearing impairments	4.7	5.6
Orthopedic impairments	17.4	21.5
Other health impairments	17.0	21.8
Mental retardation	29.4	11.8

Table 5.5 shows the number of youth successfully rehabilitated per 100,000 population aged 14-21 in each state by type of handicap. Some agencies, like Montana's, place heavy emphasis on orthopedically or other health impaired youth, whereas others such as the District of Columbia's primarily serve the mentally handicapped.

As we stated earlier, while there are undoubtedly differences in incidence rates of various handicapped conditions by state, the differences cannot be nearly as great

¹³ Incidence levels were derived by BEH from a number of sources. See U.S. Bureau of Education for the Handicapped, *Rationale for Estimates of Handicapped Children and National Manpower Needs*, October 1971.

Table 5.5
 SUCCESSFULLY REHABILITATED YOUTH PER 100,000 POPULATION: VARIOUS HANDICAP GROUPS
 BY STATE, FY 1970

State ^a	Blind	Partially Sighted	Other Visual Impairments	Deaf, Unable to Talk	Deaf, Able to Talk	Hard of Hearing	Orthopedic Impairments	Mental Health	Mental Retardation	Other Health Impairments	Speech	Other Impairments	Total All Handicaps
U.S. totals													
Number in this handicap group	249	964	4,443	900	1,081	3,672	13,520	15,974	22,862	13,249	1,378	1,524	77,816
Percent in this handicap group	0.3	1.2	5.7	1.2	1.4	2.1	17.4	20.5	29.4	17.0	1.8	2.0	100.0
Rate per 100,000 population age 14-21	1	3	15	3	4	5	45	53	75	44	5	5	260
Alabama	0.7	4	16	2	2	5	52	39	87	57	6	4	216
Alaska	0.0	6	18	2	8	6	28	47	66	23	2	8	278
Arizona	0.7	2	2	3	3	1	14	54	75	12	1	3	170
Arkansas	0.7	4	6	3	2	7	42	32	38	50	3	6	193
California	0.9	2	3	3	3	1	14	26	27	11	1	3	93
Colorado	1.1	4	13	3	5	3	62	66	89	28	3	8	286
Connecticut	1.4	8	3	1	3	2	21	129	68	14	3	8	260
Delaware	0.0	5	12	1	3	5	31	63	32	40	6	4	205
D.C.	0.9	6	33	5	5	6	41	313	247	119	7	41	825
Florida	0.3	3	16	3	3	6	40	95	118	58	6	7	355
Georgia	0.8	4	21	2	3	4	51	74	152	82	5	6	408
Hawaii	0.8	3	3	4	2	4	20	37	60	52	2	5	194
Idaho	0.0	2	17	4	7	12	86	11	36	73	2	4	252
Illinois	0.8	3	15	4	6	7	43	68	63	46	4	2	262
Indiana	0.3	2	21	4	4	6	69	8	32	46	8	1	204
Iowa	0.4	3	25	7	7	12	92	114	106	79	10	6	462
Kansas	1.7	2	4	1	4	3	46	23	34	17	3	4	148
Kentucky	1.4	2	22	3	4	9	67	87	95	71	6	28	404
Louisiana	0.4	5	38	1	2	7	120	34	73	63	8	7	364
Maine	2.0	4	10	6	4	0	35	37	42	24	1	3	169
Maryland	2.0	4	23	4	6	9	38	106	137	75	8	11	426
Massachusetts	0.0	4	11	2	5	4	41	34	56	38	2	2	200
Michigan	1.4	3	16	3	8	7	54	23	77	39	7	4	243
Minnesota	1.0	2	3	1	2	6	49	59	89	42	4	2	260
Mississippi	0.8	3	14	2	3	5	48	17	88	44	3	1	334
Missouri	0.4	3	22	5	4	10	61	50	158	41	3	7	759
Montana	0.9	2	27	2	10	11	99	19	43	58	8	8	292
Nebraska	0.4	4	16	0	6	5	50	74	72	39	5	6	292
Nevada	0.0	0	6	3	3	5	18	56	51	29	2	3	176
New Hampshire	0.0	8	6	0	1	2	25	25	44	17	3	1	134
New Jersey ^b													
New Mexico	1.2	5	4	4	6	2	45	22	68	23	2	3	185
New York	2.2	2	6	5	4	4	30	23	44	31	2	4	156
North Carolina	0.6	5	24	5	3	4	40	53	150	66	7	4	363
North Dakota	1.0	3	18	3	3	7	105	79	69	54	13	13	367
Ohio	0.6	4	13	4	6	4	37	33	51	33	5	5	197
Oklahoma	0.8	3	30	3	4	9	154	110	77	108	11	11	524
Oregon	0.6	3	4	1	2	1	12	29	26	10	1	2	93
Pennsylvania	0.2	3	32	2	2	13	53	72	79	83	9	2	351
Rhode Island	1.4	4	30	5	5	11	55	197	79	76	14	18	494
South Carolina	0.0	2	18	1	5	5	58	100	215	93	7	9	513
South Dakota	0.9	3	27	5	6	8	97	29	44	76	15	3	315
Tennessee	0.2	5	15	4	2	7	59	50	92	50	7	1	296
Texas	0.5	3	17	3	2	4	27	35	89	25	3	2	209
Utah	1.1	5	11	9	3	9	61	192	103	38	3	6	436
Vermont	0.0	0	2	4	6	1	23	26	99	20	3	7	193
Virginia	0.4	3	10	2	3	6	43	118	158	80	7	4	435
Washington	0.4	2	4	3	3	4	34	63	54	22	2	3	193
West Virginia	1.1	6	31	7	1	14	70	36	80	14	13	17	423
Wisconsin	0.9	3	15	4	3	7	69	137	127	4	5	18	434
Wyoming	0.0	0	22	0	12	10	77	98	28	47	6	10	311

^a State figures are rate per 100,000 population aged 14-21.

^b Not available.

as the differences states report in the proportion of VR youth clients that they treat with various handicaps. For example, Indiana rehabilitates 8 youths with mental health impairment per 100,000 population in the 14-21 age range, while the District of Columbia rehabilitates 313. Arizona and California each rehabilitate 14 orthopedically impaired youth per 100,000, while Oklahoma succeeds with 154. Taking all handicaps as a group, Oregon and California rehabilitate 93 youth per 100,000, while the District of Columbia rehabilitates 825.

According to the 1970 U.S. Census of Population, approximately 4,000,000 youth reach age 14 each year. Applying the BEH estimates of handicap incidence rates in the population aged 5 to 19 means that approximately 400,000 additional handicapped youth enter the eligible age range for VR services annually. It is the vocationally impaired fraction of 400,000 that the VR program should serve if it is to fill the need on a continuing basis. Our analysis of client data reported to the Federal Government indicates that the state VR agencies in 1970 had 46 percent of 400,000 referred to them, accepted about 25 percent (101,015) of that number, and successfully rehabilitated 77,816. Since we have no reliable estimate of the total youthful handicapped who are vocationally impaired, we cannot reliably estimate the unmet need. As we discuss later, however, the greatest proportion of those not accepted for service are not rejected for lack of a physical, mental, or vocational handicap, but for other reasons. Thus, it is reasonable to assume that significantly more than 25 percent of handicapped youth can benefit from vocational services.

Source of Referrals. Nearly all FY 1970 case closures reported the source of the client referral. Table 5.6 shows that the largest single source of referrals is the

Table 5.6

SOURCE OF YOUTH REFERRAL TO STATE VR AGENCIES,
FY 1970 CLOSURES

Referral Source	Not Accepted		Not Rehabilitated		Rehabilitated
Educational institutions		38.7		35.1	46.9
Elementary or high school	34.2		28.0		38.6
School for handicapped	1.8		4.7		4.8
Other educational institutions	2.7		2.4		3.5
Hospitals and sanatoriums		5.3		11.4	6.8
Health organizations and agencies		4.1		5.1	5.0
Welfare agencies		7.8		6.4	5.0
Other public organizations and agencies		25.5		25.5	16.0
Correctional or court agency	7.0		15.7		6.7
Employment service	6.1		4.5		4.5
Other public	12.4		5.3		4.8
Other private organizations and agencies		1.0		0.8	0.9
Individuals		17.6		15.7	19.4
Self-referred person	5.3		4.1		5.7
Physician	2.5		2.9		4.2
Other individual	9.8		8.7		9.5
Total		100.0		100.0	100.0

school system, which accounts for about 40 percent of the total. The health system refers only a small proportion—less than 15 percent. Also note that only about 15 percent of the youth were self-referred or came because of referral by some individual who was not connected with the public or private system serving the handicapped.

Referral Destination. Of youth referred or applying to VR agencies, only 5 percent of those not accepted are reported as being referred elsewhere by VR personnel. If this low figure indicates that VR personnel are not offering referral guidance to youth they do not accept for service, then a great opportunity exists for improving the quality of "direction" services at very low cost. Data in Table 5.7 indicate that youth are most often referred to educational institutions (22 percent) or to other public agencies (for example, of the 39 percent going to other public organizations and agencies 13 percent are sent to the employment service).

Table 5.7
AGENCIES YOUTH REFERRED TO BY VR AGENCIES, FY 1970 CLOSURES

Referral to:	Percent
Educational institutions	22
Hospitals and sanatoriums	4
Health organizations and agencies	13
Welfare agencies	16
Other public organizations and agencies	39
Other private organizations and agencies	2
Individuals	<u>4</u>
Total	100

Outcomes of Referrals to VR Agencies. Although 45 percent of referred youth aged 0-21 are not accepted into the VR program, only 5 percent are rejected as having no disabling condition, only 4 percent have no vocational handicap, and only 2 percent have too severe a handicap or an unfavorable medical prognosis. As Table 5.8 shows, the most frequent reasons for nonacceptance are that the youth refused the services (13 percent); the agency was unable to locate or contact the referred youth or he had moved (8 percent); or the youth failed to cooperate (6 percent). The significant point is that most unaccepted youth are not reported to be unqualified to receive service but are not served for other reasons.

Reasons Youth Not Rehabilitated. Of all closures not rehabilitated in FY 1970, fully one-third of the youth could not be located or contacted or had moved. The next two most prevalent reasons were refusal of services or failure to cooperate. Only 9 percent reportedly failed because of too severe a handicap or an unfavorable medical prognosis. Table 5.9 documents reasons for closures not rehabilitated from an extended evaluation status (10 percent), before services began (33 percent), and after services were initiated (57 percent).

Age, Sex, and Race. Nearly all VR agency clients are 14 or older. As shown in Table 5.10, the mode of the age distribution is 16-19, near the end of the formal schooling age range. Table 5.11 contains the age breakdown by type of handicap.

Table 5.8
OUTCOMES OF REFERRING YOUTH TO VR AGENCIES

Outcome	Percent Referred
Accepted	52
Extended 6- or 12-month evaluation	3
Not accepted	45
Unable to locate or contact, or moved	8
Handicap too severe or unfavorable medical prognosis	2
Youth refused services	13
Death	<1
Client institutionalized	<1
Transfer to another agency	<1
Failure to cooperate	6
No disabling condition	5
No vocational handicap	4
Other, or reason not given	6
Total	100

Table 5.9
REASONS YOUTH NOT REHABILITATED IN VR PROGRAM

Reason	Percent of Closures:			Percent of Total Closures Not Rehabilitated
	From Evaluation Status	Before Rehabilitation Services Began	After Rehabilitation Services Began	
Unable to locate or contact, moved	2	10	21	33
Handicap too severe, or unfavorable medical prognosis	2	2	5	9
Youth refused services	2	10	8	20
Death	0	1	2	3
Client institutionalized	1	2	4	7
Transfer to another agency	0	0	1	1
Failure to cooperate	1	5	9	15
No disabling condition	0	0	0	0
No vocational handicap	0	0	0	0
Other, or reason not given	2	5	7	13
Total	10	33^a	57	100^a

^a Rows and columns do not total precisely due to rounding.

Table 5.10
PERCENT OF VR CLIENTS BY AGE GROUP, FY 1970 CLOSURES

Outcome	Age Group					Total
	0-13	14-15	16-17	18-19	20-21	
Not accepted	1.4	7.3	33.4	34.6	23.3	100
Not rehabilitated	1.8	10.7	33.2	31.4	22.9	100
Rehabilitated	1.3	7.4	34.5	34.8	22.0	100

Table 5.11
PERCENT OF REHABILITATED CLIENTS BY AGE AND
HANDICAP GROUPS, FY 1970 CLOSURES

Handicap Group	Age Group				
	0-13	14-15	16-17	18-19	20-21
Blind	1.2	10.7	46.4	21.4	20.2
Partially sighted	3.2	7.8	32.6	33.7	22.7
Other visual impairments	1.4	2.6	34.7	39.7	21.6
Deaf, unable to talk	1.4	7.6	28.7	40.1	22.1
Deaf, able to talk	1.6	3.8	31.7	40.0	22.9
Hard of hearing	2.0	3.5	34.8	38.1	21.6
Orthopedic impairment or absence of extremities	1.7	1.6	28.8	41.0	26.7
Mental illness	0.8	7.4	32.0	32.1	27.7
Mental retardation	1.1	16.1	43.5	27.1	12.2
Other health impairments	1.5	1.5	31.0	40.4	26.6
Speech impairments	1.7	2.8	34.6	44.5	16.4
Other impairments	1.4	3.6	29.7	44.5	29.8
Total	1.3	7.4	34.5	34.8	22.0

Of youth referred or applying for vocational rehabilitation, 38 percent were female and 62 percent were male. The percentage breakdown is the same for those successfully rehabilitated.

Of youth successfully rehabilitated, 81 percent were Caucasian and 18 percent were Negro; 78 percent and 21 percent of all referrals or applicants were Caucasian and Negro, respectively. For comparison, the 1970 Census of Population indicated that 87 percent of the United States population was Caucasian.

Education. Table 5.12 gives the distribution of educational achievement by levels of VR clients. Excluding those from Mental Retardation classes, the median grade completed was 11 for both FY 1970 referrals and for those served but not rehabilitated, while the median grade completed for those successfully rehabilitated was 12. Employer's use of the high school diploma as a job prerequisite may partially explain the higher success rate with those who completed the twelfth grade.

Secondary Disabilities. In addition to prime disabling conditions, 20 percent of the youth accepted for VR services had a secondary disabling condition. Table 5.13 shows that these secondary conditions were most often an orthopedic, mental health, mental retardation, or other health impairment.

Table 5.12

PERCENT OF YOUNG VR CLIENTS BY EDUCATIONAL LEVELS,
FY 1970

Highest Grade Completed	Not Accepted	Not Rehabilitated	Rehabilitated
0-6	10	3	2
7-9	17	20	12
10-11	27	21	19
12	28	22	31
13-20	4	3	5
MR class ^a	14	31	31
Total	100	100	100

^aMental retardation class.

Table 5.13

PERCENT OF YOUNG VR CLIENTS WITH SECONDARY DISABILITIES
FY 1970 CLOSURES

Secondary Disability Group	Not Rehabilitated	Rehabilitated
Blind	<1	<1
Partially sighted	<1	<1
Other visual impairments	2	2
Deaf, unable to talk	<1	<1
Deaf, able to talk	<1	<1
Hard of hearing	<1	1
Orthopedic impairments or absence of extremities	3	2
Mental illness	4	3
Mental retardation	3	2
Other health impairments	5	6
Speech impairments	1	1
Other impairments	2	1
No secondary disability	80	81
Total	100	100

Source of Applicant Support. As would be expected, considering that we are studying youth, over two-thirds report family and friends as their prime source of support. Seven percent of those accepted for service are primarily self-supporting from current earnings, interest, dividends, or rental income. Table 5.14 indicates the distribution of sources of support.

Monthly Family Income. The median monthly income for families of youth referred to state VR agencies is approximately \$300. As shown in Table 5.15, however, nearly one-third had less than \$150 per month and only 17 percent had over \$600 per month.

Table 5.14

PERCENT OF YOUNG VR APPLICANTS BY SOURCE OF SUPPORT, FY 1970

Primary Source of Support	Not Accepted	Not Rehabilitated	Rehabilitated
Current earnings, interest, dividends, rent	17	5	8
Family and friends	70	66	77
Private relief agency	<1	<1	<1
Public assistance, at least partly with Federal funds	5	6	4
Public assistance without Federal funds	1	1	<1
Public institution, tax supported	5	19	8
Workmen's Compensation	<1	<1	<1
Social Security Disability Insurance	<1	<1	<1
Other disability, sickness, survivors, or age retirement (except private insurance); unemployment insurance benefits	1	1	1
Annuity and other non-disability insurance benefits (private insurance)	<1	<1	<1
Disability or sickness benefits (private insurance); savings; other sources	<1	<1	<1
Total	100	100	100

Table 5.15

PERCENT OF YOUNG VR APPLICANTS BY MONTHLY FAMILY INCOME, FY 1970

Income Range	Not Accepted	Not Rehabilitated	Rehabilitated
\$ 0-149	30	34	21
150-199	6	6	7
200-249	8	8	9
250-299	6	6	7
300-349	7	8	9
350-399	5	5	6
400-449	8	7	9
450-499	4	4	5
500-599	8	7	9
600 and over	18	15	18
Total	100	100	100

Clients on Public Assistance. Only 9 percent of all youth referred for VR services were receiving public assistance at referral. Less than 2 percent of referrals received Aid to the Blind or to the Permanently and Totally Disabled. As shown in Table 5.16, the most frequent type of public assistance received was Aid to Families with Dependent Children. As indicated earlier, these youth are generally supported by family funds rather than by welfare funds. At closure, only 3 percent of successful rehabilitants need public assistance. While the VR youth program does reduce current welfare costs somewhat, the most significant reduction should be in future public assistance after the youth becomes an adult and may not be supported by his family.

Table 5.16
PERCENT OF YOUTH IN PUBLIC ASSISTANCE CATEGORIES,
FY 1970 CLOSURES

Public Assistance Category	At Time of Referral			At Time of Closure	
	Not Accepted	Not Reheb	Rehab	Not Reheb	Rehab
Not receiving Public Assistance	91	89	92	93	97
Aid to the Blind	<1	<1	<1	<1	<1
Aid to Permanently and Totally Disabled	1	1	1	2	<1
Aid to Families with Dependent Children only	5	6	4	3	1
General Assistance only	1	2	1	1	<1
AFDC in combination with other types	<1	<1	<1	<1	<1
Any other combination of above types	<1	<1	<1	<1	<1
Type unknown	1	2	2	<1	<1
Public Assistance received between VR referral and closure only	0	0	0	<1	<1
Total	100	100	100	100	100

Client Status, Social Security Disability Insurance. As shown in Table 5.17, approximately 2 percent of the FY 1970 young VR closures were allowed SSDI benefits.

Client Earnings and Work Status. For successfully rehabilitated youth in FY 1970, only 11 percent worked during the week preceding referral, as compared to 100 percent at closure. In addition, average reported weekly earnings for those working at referral were only \$51, while average reported earnings at closure were \$76.¹⁴ The average weekly earnings of rehabilitated VR clients of all ages was also \$76. Tables 5.18 and 5.19 provide detailed breakdowns of the work status categories and earnings for youth not accepted and not rehabilitated. In contrast, the median

¹⁴ These figures exclude those working as homemakers, unpaid family workers, and a few who did not report any earnings.

Table 5.17

PERCENT OF YOUTH IN SSDI STATUS CATEGORIES, FY 1970 CLOSURES

Social Security Disability Insurance Status	At Time of Referral			At Time of Closure	
	Not Accepted	Not Rehab	Rehab	Not Rehab	Rehab
Not an applicant	87	96	97	94	98
Applicant, allowed benefits	2	2	1	2	1
Applicant, denied benefits	2	<1	<1	<1	<1
Application pending	1	1	1	<1	<1
Unknown	7	<1	<1	2	<1
Benefits discontinued or terminated	<1	<1	<1	<1	<1
Total	100	100	100	100	100

Table 5.18

PERCENT OF YOUTH IN VARIOUS WORK STATUS CATEGORIES, FY 1970 CLOSURES

Work Status Category	At Time of Referral			At Time of Closure	
	Not Accepted	Not Rehab	Rehab	Not Rehab	Rehab
Competitive labor market	12	5	10	8	87
Sheltered workshop	<1	<1	<1	<1	4
Self-employed	<1	<1	<1	<1	<1
State agency managed business enterprise	<1	<1	<1	<1	<1
Homemaker	1	1	1	2	7
Unpaid family worker	<1	<1	<1	1	2
Not working, student	41	39	48	17	0
Not working, other	45	54	40	71	0
Trainee or worker (non-competitive labor market)	1	1	1	1	0
Total	100	100	100	100	100

Table 5.19

AVERAGE WEEKLY EARNINGS OF VR CLIENTS UNDER AGE 22, FY 1970 CLOSURES

Category	Average Weekly Earnings	
	At Referral	At Closure
Not accepted	\$57	--
Not rehabilitated	\$49	\$67
Rehabilitated	\$51	\$76

May 1970 weekly earnings of salaried workers aged 16 to 24 was \$88 and \$112 for females and males, respectively.¹⁵

In aggregate terms, the estimated total annualized earnings based on weekly earnings of all rehabilitated youth rose from \$20,637,000 at time of referral to \$279,851,000 at time of closure.

Services Provided to Youth. All VR clients receive some services directly from the state agency's rehabilitation counselors, such as vocational planning, counseling, and job placement. In addition, most receive one or more specialized services for individuals:¹⁶

- Diagnostic and evaluation—including transportation, hospital and professional fees for medical, psychological, social, and vocational diagnostic and evaluation services to determine eligibility or scope of other services needed.
- Restorative—medical or medically-related services to correct or substantially modify a physical or mental condition.
- Training—including training materials, tools and equipment; training in a college, university, high school or elementary school, business school, vocational school; or on-the-job and training in personal and vocational adjustment.
- Income Maintenance—basic living expenses, if necessary.
- Service to other family members—services that contribute substantially to rehabilitation of the handicapped youth.
- Other services—including reader or interpreter services, occupational tools and equipment, initial stocks, licenses or transportation.

Table 5.20 shows the percentage of young VR clients receiving each of the above class of services. The youth who are not rehabilitated receive fewer services on the average, primarily because one-third of their cases are closed before any services are given. Nearly all clients receive diagnostic and evaluation services, but less than 33 percent require physical or mental restorative services. Seventy-six percent of those rehabilitated receive training, while only 56 percent of those not rehabilitated are trained. Less than 30 percent need income maintenance while receiving other VR services, and only 2 to 3 percent of the youths' families receive special services. The mix of services delivered to rehabilitated VR clients of all ages differs from the mix delivered to youth, since nearly half of all clients receive restoration, while only 47 percent of all clients receive training.

Time Spent in Program. The average time between referral of youth and acceptance for service is 6 months. The average time from acceptance to closure is 15 months, for a total of 21 months' average time from referral to case closure.

Expenditures for Youth VR in FY 1970. Estimated expenditures for persons aged 0-21 under the State-Federal VR Program in FY 1970 were \$131,305,000. This figure translates into \$1300 per youth served, \$1687 per youth successfully rehabilitated, and \$6.49 for each person aged 14-21 in the United States in 1970. Table 5.21 shows the expenditure rates across states; for example, Maryland and Utah spend less than \$300 per youth rehabilitated, while Alaska spends more than

¹⁵ M. P. Flaim and N. Peters, "Usual Weekly Earnings of American Workers," *Monthly Labor Review*, Vol. 95, No. 3, March 1972, p. 30.

¹⁶ See U.S. Department of Health, Education, and Welfare, *Vocational Rehabilitation Manual*, "Statistical Reporting Procedures," Chap. 13, July 1969.

Table 5.20
 PERCENT OF YOUNG VR CLIENTS RECEIVING SERVICES BY HANDICAP GROUP, FY 1970 CLOSURES

Handicap Group	Services											
	Diagnosis and Evaluation		Restoration		Training		Income Maintenance		Service to Other Family Members		Other Services	
	Not Rehab	Rehab	Not Rehab	Rehab	Not Rehab	Rehab	Not Rehab	Rehab	Not Rehab	Rehab	Not Rehab	Rehab
Blind	95	93	31	33	95	85	44	57	3	7	53	60
Partially sighted	89	91	15	37	57	81	23	49	<1	2	33	40
Other visual impairments	96	96	28	46	42	72	14	29	<1	1	15	24
Deaf, unable to talk	94	97	22	35	63	83	19	36	3	9	30	44
Deaf, able to talk	98	96	37	53	54	78	31	30	4	5	22	33
Hard of hearing	98	96	24	57	32	70	8	30	3	3	13	24
Orthopedic impairment or absence of extremities	93	95	26	33	52	82	29	35	3	3	23	29
Mental illness	89	92	21	34	58	73	28	36	2	3	28	36
Mental retardation	95	96	10	14	59	79	22	25	3	4	22	33
Other health impairments	95	94	27	48	46	67	20	24	1	2	21	24
Speech impairments	94	96	33	45	38	77	16	35	<1	1	15	24
Other impairments	75	93	22	43	62	70	21	30	1	4	23	32
Total	92	95	20	33	56	76	24	30	2	3	24	31

Table 5.21
ESTIMATED EXPENDITURES FOR YOUTH VR BY STATE, FY 1970 CLOSURES

State	Total Cost of Services ^c (000)	Service Cost as Percent of Total Expenditures ^a	Estimated Total Expenditures ^b (000)	Average Expenditures		Expenditures per Total Population Aged 14-21
				Accepted	Rehabilitated	
U.S. total	\$73,531	56	\$131,305	\$1,300	\$1,687	\$ 6.49
Alabama	2,290	55	4,164	2,057	2,800	7.78
Alaska	180	38	474	2,370	4,514	9.74
Arizona	623	52	1,198	1,920	2,599	4.42
Arkansas	846	72	1,175	1,438	2,148	4.15
California	2,795	52	5,375	1,073	1,958	1.84
Colorado	1,182	64	1,847	1,328	1,834	5.25
Connecticut	1,006	50	2,012	1,461	1,865	4.85
Delaware	172	30	573	2,274	3,473	7.12
D.C.	387	35	1,106	914	1,206	8.22
Florida	2,254	48	4,696	1,042	1,450	5.15
Georgia	1,928	67	2,878	763	992	4.04
Hawaii	250	45	556	1,308	2,336	4.54
Idaho	171	47	364	1,064	1,277	3.22
Illinois	4,324	63	6,863	1,485	1,667	4.36
Indiana	1,302	69	1,887	1,070	1,186	2.41
Iowa	1,371	50	2,742	1,123	1,416	6.54
Kansas	384	54	711	915	1,394	2.05
Kentucky	1,107	49	2,259	938	1,134	4.51
Louisiana	2,118	67	3,161	1,143	1,462	5.39
Maine	340	60	567	1,703	2,296	3.88
Maryland	647	35	1,849	603	769	3.27
Massachusetts	2,399	68	3,528	1,704	2,164	4.32
Michigan	2,138	45	4,751	1,040	1,441	3.50
Minnesota	907	51	1,778	1,036	1,187	3.09
Mississippi	976	43	2,270	2,106	3,188	6.28
Missouri	2,320	58	4,172	1,284	1,687	6.22
Montana	259	67	387	1,022	1,229	3.58
Nebraska	582	57	1,021	1,213	1,566	4.57
Nevada	96	29	331	1,329	2,904	5.10
New Hampshire	140	54	259	1,239	1,811	2.43
New Jersey ^c						
New Mexico	287	45	638	1,227	2,106	3.79
New York	7,621	70	10,887	2,035	2,843	4.42
North Carolina	2,152	51	4,220	1,256	1,404	5.08
North Dakota	435	58	750	1,777	2,022	7.43
Ohio	2,785	44	6,330	1,582	2,032	4.02
Oklahoma	1,420	63	2,254	890	1,130	5.92
Oregon	295	54	546	878	1,876	1.74
Pennsylvania	9,060	67	13,672	1,762	2,343	8.22
Rhode Island	653	59	1,107	1,337	1,572	7.76
South Carolina	1,037	42	2,469	959	1,088	5.58
South Dakota	423	56	755	1,907	2,234	7.02
Tennessee	1,182	56	2,111	1,036	1,205	3.55
Texas	2,530	53	4,774	1,018	1,320	2.76
Utah	343	57	602	623	762	3.31
Vermont	227	47	483	2,583	3,604	6.97
Virginia	2,156	61	3,534	919	1,131	4.91
Washington	678	50	1,356	944	1,345	2.59
West Virginia	1,257	72	1,746	1,276	1,562	6.50
Wisconsin	3,033	69	4,396	1,317	1,517	6.58
Wyoming	289	54	535	2,306	3,386	10.51

^aU.S. Department of Health, Education and Welfare, State Vocational Rehabilitation Agency: Program Data FY 1971, Social and Rehabilitation Service, DHEW Publication No. (SRS) 72-25016, March 1972.

^bAssuming services cost as percentage of expenditures is same for both youth and adults.

^cNot available.

\$4500, and the expenditures per total population aged 14-21 vary from \$1.74 in Oregon to \$10.51 in Wyoming. Table 5.22 gives the expenditures by disability group.

While the estimated average expenditure rate per youth rehabilitated was \$1687, the rates per blind and partially-sighted youth rehabilitated were \$6514 and \$4437, respectively. In contrast, average expenditures per rehabilitated mentally retarded youth and deaf youth who are unable to talk were only \$1361 and \$2151, respectively. Even allowing for the differences in services needed by various handicap groups, there clearly are large unexplained differences in the expenditure rates for the various handicap groups. A subsequent Rand report will deal with the relationships between expenditures and services delivered and the individual's vocational success.

The average cost of case services for rehabilitated youth was \$804, considerably higher than the \$709 average for comparable clients of all ages. Note that program administration costs and counseling and placement by VR counselors are not included in the category of reported costs for services to individuals; thus, less than 100 percent incurred case service costs. Also, since the costs for services to individuals do include diagnostic and evaluation expenses, some of those not accepted into the VR program had reported service costs. The FY 1970 case closures show costs for case services to individuals of 34 percent for those not accepted, 85 percent for those accepted but not rehabilitated, and 92 percent for those successfully rehabilitated.

Basic State-Federal Program Expenditures in FY 1972 ¹⁷

While detailed data are not yet available on clients given vocational rehabilitation services in FY 1972, the Federal expenditures for the basic state grants were \$560,000,000, with an additional \$58,148,891 for service projects to all age groups. The states devoted an estimated additional \$141,762,553 and \$1,400,000 for the basic VR program and service projects, respectively. Of the Federal funds, approximately \$134,000,000 of the basic state grant and \$13,900,000 of the service project monies were for services to persons aged 0-21.¹⁸ The portion of state funds used for the basic VR program and for service projects that reach youth aged 0-21 were estimated to be \$34,023,000 and \$336,000, respectively.

For clients of all ages, the service projects in 1972 included \$42,098,891 for grants to expand services to the handicapped beyond that possible under the basic State-Federal VR Program. Expansion grants focused on handicapped persons who were disadvantaged or severely disabled. An additional \$1,000,000 was expended on projects to develop employment opportunities for handicapped persons in particular industries. Another \$2,000,000 was spent on training individuals for new career opportunities in service to the handicapped. A total of \$550,000 was for initial staffing of new or renovated rehabilitation facilities. \$12,500,000 was for rehabilitation facility improvement, including \$7,850,000 for training workers, \$4,450,000 to increase and improve professional services to the handicapped, business management, and other aspects of rehabilitation facilities. The remaining \$200,000 was for short-term technical assistance to rehabilitation facilities by consultants.

¹⁷ FY 1972 data from U.S. Department of Health, Education and Welfare, *Justifications of Appropriation Estimates*.

¹⁸ Assuming the 24 percent of total FY 1970 basic state grant expenditures devoted to serving handicapped persons aged 0-21 also is valid for FY 1972 and for service projects.

Table 5.22
ESTIMATED EXPENDITURES FOR YOUTH VR BY DISABILITY GROUP, FY 1970 CLOSURES

Handicap Group	Total Cost of Services (000)	Estimated Total Expenditures ^a (000)	Average Expenditures per Youth		Percent of Expenditures Incurred by Handicap Group	Average Cost of Services per Youth		
			Accepted	Rehab		Not Accepted	Accepted	Rehab
Blind	\$ 908	\$ 1,622	\$5,037	\$6,514	1.2	\$31	\$2,796	\$3,227
Partially sighted	2,395	4,277	3,463	4,437	3.3	27	1,927	2,179
Other visual impairments	4,193	7,488	1,441	1,685	5.7	13	791	877
Deaf, unable to talk	1,084	1,936	1,691	2,151	1.5	17	941	1,081
Deaf, able to talk	1,224	2,186	1,725	2,022	1.7	15	958	1,048
Hard of hearing	1,624	2,900	1,502	1,734	2.2	14	824	910
Orthopedic impairments or absence of extremities	17,373	31,024	1,884	2,295	23.7	13	1,044	1,142
Mental illness	12,133	21,666	902	1,356	16.5	19	484	557
Mental retardation	17,422	31,111	1,049	1,361	23.7	21	575	632
Other health impairments	12,262	21,897	1,375	1,653	16.7	16	751	827
Speech impairments	1,440	2,571	1,598	1,866	1.9	12	886	982
Other impairments	1,471	2,627	1,209	1,724	2.0	17	660	701
Total	\$73,531	\$131,305	\$1,300	\$1,687	100.0	\$18	\$ 713	\$ 804

^a Assumes that the United States average of 56 percent of total expenditures on "services to individuals" holds for each group of handicapped youth. Only 1 percent of the youth accepted into the VR programs are eligible to have the Social Security Trust Fund pay costs. These costs are included in the totals presented above.

Table 5.23 shows the estimated breakdown of expenditures for FY 1972 by handicap, assuming that the breakdown of the basic State-Federal VR Program expenditures by type of handicap in FY 1972 was the same as for FY 1970.

Table 5.23

ESTIMATED EXPENDITURES FOR THE BASIC STATE-FEDERAL VR YOUTH PROGRAM
BY DISABILITY GROUP, FY 1972

Handicap Group	Estimated Total Expenditures
Blind	\$ 2,000,000
Partially sighted	5,500,000
Other visual impairments	9,600,000
Deaf, unable to talk	2,500,000
Deaf, able to talk	2,800,000
Hard of hearing	3,700,000
Orthopedic impairments or absence of extremities	39,800,000
Mental illness	27,700,000
Mental retardation	39,800,000
Other health impairments	28,000,000
Speech impairments	3,200,000
Other impairments	3,400,000
Total	\$168,000,000

Training VR Personnel

In providing skilled manpower to meet VR program needs, the FY 1972 Federal appropriations were \$27,700,000—\$26,200,000 for 440 long-term training projects and \$1,500,000 for 100 short-term training projects. The long-term training includes an estimated 5300 traineeships awarded to students. Also, approximately 6500 personnel underwent short-term training in FY 1972 to improve and update their VR knowledge. The estimated 1972 average employment level of state agency staff totaled 25,575 man-years, of which 3075 were for administration, 16,900 were for counseling and placement, and 5600 were for staff at state VR agency operated facilities. It has been estimated that 3700 new state rehabilitation program staff positions and 1000 additional private program staff positions are required in FY 1973 to serve the projected client load. Thus, the present training program meets only a fraction of the need for new vocational rehabilitation staff. In addition, it is estimated that 30,000 jobs are presently available for health-related rehabilitation personnel such as occupational and physical therapists, and speech pathologists.¹⁹

Since 25 percent of the clients in state VR agencies are 21 and under,²⁰ and assuming approximately that percentage of VR staff members' time is devoted to

¹⁹ Information above is condensed from *Justifications of Appropriation Estimates*.

²⁰ U.S. Department of Health, Education and Welfare, Forms RSA-300, *Case Service Report—Federal State Program of Vocational Rehabilitation, FY 1970*.

younger clients on the average, then we estimate \$6,925,000 of the total funds devoted to training personnel will benefit handicapped youth.

Construction and Improvement of Rehabilitation Facilities

Development of new facilities and improvement of old ones are funded principally under Secs. 2 and 12 of the Vocational Rehabilitation Act. In FY 1972 the total Sec. 12 expenditures were \$3,051,000 for one facility construction project; and no funds were requested by HEW for this section for FY 1973.²¹

Section 2 is the basic Federal grant-in-aid program to the states. Actual total Federal and state matching Sec. 2 expenditures for facilities in FY 1971 were \$45,288,730; of this total \$37,012,785 was to assist in establishing rehabilitation facilities and workshops, \$968,997 was capital expense for state agency operated rehabilitation facilities, and \$7,306,948 was for construction.²² Compared with the high cost of facilities, these direct Federal and state expenditures are relatively minor. It is apparent that most current funding of construction and improvement of facilities does not come directly from the Federal and state governments. Rather, those facilities are largely created by other funding sources. Over the long run, however, they are indirectly and partially financed by payments to facilities for serving clients of the State-Federal VR program. Again assuming that approximately 25 percent of the clients accepted into the state VR agencies are 21 and under, and assuming approximately that percentage of the facilities are devoted to younger clients, we then estimate approximately \$12,085,000 is spent annually to construct and improve rehabilitation facilities utilized for youth.

SRS Administered Research and Demonstration

In FY 1972, the U.S. Social and Rehabilitation Service (SRS) administered Research and Demonstration funds relevant to handicapped youth that were included as part of the \$19,255,000 devoted to rehabilitation and employability, \$525,000 expended on Social Security programs, and \$13,941,000 devoted to special centers, or roughly \$32,000,000 in all. The special centers included 19 Rehabilitation Research and Training Centers (12 Medical, 3 Mental Retardation, 3 Vocational, and 1 Deafness), 1 National Center for Deaf-Blind Youths and Adults (research, training personnel, and service to about 150 clients annually) and 16 Regional Research Institutes (expenditure of \$1,500,000 serving all program components of SRS).²³ While all of the expenditures are relevant to handicapped youth in that they may yield results that will improve services to younger disabled persons, they are also obviously relevant to disabled adults and to aged and low-income persons. Of the \$32,000,000 in Research and Demonstration funds, we estimate that \$6,700,000 or

²¹ *Justifications of Appropriation Estimates.* For a more detailed discussion of legislation relating to facilities, see U.S. Department of Health, Education and Welfare, *Rehabilitation Facility Needs in the 1970s*, Rehabilitation Services Administration, Monograph No. 1.

²² U.S. Department of Health, Education and Welfare, *State Vocational Rehabilitation Agency: Program Data, Fiscal Year 1971.*

²³ *Justifications of Appropriation Estimates.*

21 percent goes to handicapped youth, since approximately 21 percent²⁴ of the U.S. population who have some chronic physical or mental condition that may result in limited activity are under 22.

Federal Administration of the Social and Rehabilitation Service Programs

The operational costs of administering the Social and Rehabilitation Service within the U.S. Department of Health, Education and Welfare were \$44,175,000 in FY 1972. The SRS staff totaled 2382 that year.²⁵ Table 5.24 shows the staff's administrative composition.

We estimate that the percentage of total program expenditures on VR assistance to handicapped persons up through age 21 is 25 percent of total VR expenditures.²⁶ Assuming the administrative expenditures are proportional to staff size, and that staff time is divided in roughly the same way as expenditures within each program, we estimate that \$1,705,000 of the SRS administration cost can reasonably be allocated to VR activities for handicapped youth.

Table 5.24

SRS ADMINISTRATION STAFF

Program Area	SRS Staff Positions
Maintenance assistance	511
Medical assistance	586
Community services	482
Rehabilitation services	368
Services for the aging	120
Youth development and delinquency	69
Research and training	<u>246</u>
Total	2382

OTHER VOCATIONAL PROGRAMS

Besides the basic State-Federal VR Program, there are four major vocationally-related programs: Committees on Employment of the Handicapped; Federal employment of the handicapped; the vending stand program for the visually handicapped; and the Employment Services Program. The focus of these four programs is on employment rather than on vocational rehabilitation.

²⁴ U.S. Department of Health, Education and Welfare, *Limitation of Activity and Mobility Due to Chronic Conditions, United States, July 1965-June 1966*, National Center for Health Statistics, PHS Publication No. 1000, Series 10, No. 45. We note that as in any case in which one allocates overhead costs, the estimate is somewhat artificial because we don't really know what the overhead expenditures would have been if there were no handicapped youth to consider.

²⁵ *Justifications of Appropriation Estimates*.

²⁶ Based on analysis of U.S. Department of Health, Education and Welfare Forms RSA-300.

Committee on Employment of the Handicapped

The Presidential Committee on Employment of the Handicapped, the corresponding Governor's Committees on Employment of the Handicapped in the 50 states, and hundreds of local committees promote employment opportunities for the mentally and physically impaired. Primarily, these committees endeavor to educate potential employers and the public regarding the vocational abilities of the handicapped. Thus, they try to help the impaired population in general, rather than providing placement services for persons individually. Many of the committees are also active in backing legislation to remove barriers to employment of the handicapped, e.g., physical obstacles in the areas of architecture and transportation.

The FY 1972 budget estimate for the Presidential Committee was \$726,000 for persons of all ages. Since, as described earlier, approximately 21 percent of the United States population who have some chronic physical or mental condition that may limit their activities are under age 22, we estimate that 21 percent of the \$726,000 budget, or \$152,000, goes to handicapped youth. Governor's Committee budgets and staffs are small. The Massachusetts Committee, for example, runs on \$450 annually with two staff members loaned from the state employment service; Illinois, however, has an exceptionally high annual budget of \$146,000.²⁷

Federal Employment for the Handicapped

The Civil Service Commission provided assistance to 8046 handicapped persons seeking Federal employment in FY 1969. Budget obligations in FY 1970 and FY 1972 were \$70,000 and \$72,000, respectively.²⁸

The Randolph-Sheppard Vending Stand Program

In FY 1971 a total of 3454 blind and visually handicapped persons operated vending stands in governmental buildings and earned an average of \$6540 each from the businesses.²⁹ It is assumed that only a small fraction of the operators are under 21.

Employment Services

In FY 1970 the Federal Government budgeted \$348,000,000 for grants to states for employment services, including interviewing, counseling, and job placement referrals for individuals. This amount averaged \$35 for each of the 9,957,000 applicants for services in that year. The objective of these services is not vocational rehabilitation, but rather the matching of potential employees with employers. Special attention reportedly is given to the physically and mentally handicapped and other disadvantaged groups.

²⁷ Financial data from staff members of the Illinois and Massachusetts Governor's Committees on Employment for the Handicapped.

²⁸ *Catalog of Federal Domestic Assistance*, Executive Office of the President, Office of Management and Budget, 1972.

²⁹ *Justifications of Appropriation Estimates*.

The total nonagricultural placements of handicapped persons in the United States in FY 1969 were 324,000, of which an unknown percentage was under 21. The growth in the number of handicapped served is relatively low; the number grew only 22,900 from 1966 to 1969.³⁰ Assuming that the percentage of clients under 22 is the same for both the employment service and the VR programs, and conservatively assuming that the handicapped person costs the same to place as the average person, then we estimate that approximately \$3,350,000 was expended in delivering employment services to handicapped youth in FY 1970. By assuming that the fraction of employment service funds expended on handicapped youth was the same in FY 1970 and FY 1972, we estimate that approximately \$3,750,000 was expended in delivering employment services to handicapped youth in FY 1972.

SURVEY RESPONSES FROM STATE VOCATIONAL REHABILITATION AGENCIES

The survey of state agencies described in Appendix B included 88 vocational rehabilitation agencies in 50 states. Thirty-eight of those agencies serve only visually impaired persons, while the remainder serve handicapped persons in general. Only 24 agencies responded to the mail survey; of these we interviewed personnel in six agencies as we were developing the questionnaire. The principal reason for the low response rate concerns a new evolving policy of the National Council of State Administrators of Vocational Rehabilitation; it will act as a clearinghouse, approving surveys state agencies should respond to, in order to lessen the burden of responding to the several surveys state agencies typically receive each week. When the mail questionnaire for this research project was developed in conjunction with HEW's Rehabilitation Services Administration, the Council of State Administrators' evolving policy of requiring prior Council approval of all questionnaires had not yet been implemented by establishment of a survey review committee. Many state administrators were rejecting all surveys, however, even those such as Rand's, which had the approval of the Rehabilitation Services Administration and the Office of the Secretary of the U.S. Department of Health, Education and Welfare. As the Council of State Administrators' new policy is being implemented the transition is bound to be somewhat difficult, but we concur with their policy and objectives of lessening the excessive survey response burden. The policy should also improve the quality and quantity of responses to surveys that receive Council clearance.

The thousands of pages of descriptive material returned by respondents to the Rand survey provided a great deal of information that was extremely helpful in developing this particular section and that will be used in preparing a subsequent report on recommendations for improving programs for sensorially impaired youth. In return for supplying the information, the state agencies should benefit from the data in this report, which provide a current picture of services to young clients in many other states, and thus offer a baseline against which to measure their own services to youth.

In addition to descriptive information, the 24 responding agencies made many comments on problem areas in current programs. The most frequently cited problem

³⁰ Data from Manpower Administration, U.S. Department of Labor, Washington, D.C.

was insufficiency of funds (15 respondents). The next most frequently mentioned problem was inadequate coordination between different agencies providing services to the handicapped (8 respondents). Five agencies cited problems because of Federal funding decisions made late in the fiscal year and the unpredictability of funding levels, while four indicated that agencies make little attempt at outreach programs to identify people needing service. All of the following problems were cited by three or fewer respondents: inequity in service delivery by type of handicap; geographic inequity in service delivery; expansion of the groups to be served (e.g., addicts, criminals) without a corresponding increase in funds; inadequate prevocational preparation of youth by the schools (e.g., mobility, reading ability); short supply of professional personnel; short supply of physical facilities; too few rehabilitation counselors trained to communicate fluently with deaf persons; difficulty in deciding whom to serve because of broad and vague definitions of handicaps; insufficient flexibility because of too specific guidelines on types of handicapped persons to be served; transportation barriers to employment; architectural barriers to employment; acceptance of clients affected by desires of agency more than needs of clients; quantity rather than quality orientation of VR agencies; state unwilling to fully match available Federal funds; unknown extent of population needing service; inadequate quality of state employment service; excessive Federal reporting requirements; need for more preschool, psychological, and vocational services specifically designed for the visually handicapped; lack of handicapped persons on VR advisory boards; special facilities and programs insufficiently available to serve the increasing number of multiply handicapped persons; and duplication of services offered in different state agencies.

PREVIOUS STUDIES AND DATA AVAILABILITY

Excellent data are collected and available in computer-processible form on each person referred for VR services in the states. These data give detailed information on client characteristics, services rendered, and the effect of those services. While we could point to a few specific deficiencies in the reporting system and data, the quality of the data is better than that available for any other Federal program serving handicapped youth. The various reports and analyses issued by the Rehabilitation Services Administration are also exemplary when compared to those available on other programs described in Secs. 6 through 10 of this report.

While we are not aware of any previous general study aimed at analyzing vocational rehabilitation services for youth, there are several studies that looked at VR services for persons of all ages and produced information relevant to this research. In this subsection we examine the State-Federal program data, a report of the National Citizens Advisory Committee on Vocational Rehabilitation, several surveys providing information on VR, two cost-benefit studies of this program, several analyses dealing with VR services in general, and three studies that looked at a broad range of services to either youth or the handicapped. These latter three studies are presented primarily for their methodological interest. The studies reviewed here are only a few of the more than 100 that we examined in detail. They are some, but certainly not all, of the better quantitative studies relevant to overall

VR program description, and they provide a reasonably accurate picture of the rehabilitation program and data availability.

National Citizen's Advisory Committee on Vocational Rehabilitation, *Report of the National Citizen's Advisory Committee on Vocational Rehabilitation*, submitted to the Secretary of Health, Education and Welfare, June 26, 1968. The National Citizen's Advisory Committee on Vocational Rehabilitation was authorized by the Congress and appointed by the Secretary of the Department of Health, Education and Welfare in 1966 to make a "... comprehensive study of the current vocational rehabilitation program and of the nation's vocational rehabilitation needs ..." and to "... formulate goals for the program and make specific recommendations for arriving at those goals." In 1968 the Committee issued a report containing numerous recommendations including, for example, the following areas: increased appropriations; strengthening of private voluntary agencies; increased emphasis and special services for the severely handicapped; increased efforts for employment of the handicapped, e.g., on-the-job training within industry through government subsidy if necessary; improved referral systems; decentralization and dispersal of VR offices in major population centers; and increased funds for service personnel training.

With respect to handicapped children the Committee recommended:

- Establishment of cooperative school-rehabilitation programs in all schools, public and private, in both urban and rural locations, including a central repository of health and rehabilitation records.
- Evaluations of disabled children for rehabilitation purposes by vocational rehabilitation personnel at regular intervals during the elementary and junior high years—for example, at ages 8, 12, and 14—to help prepare the child for a meaningful adult vocational career.
- Legislation to permit furnishing physical restoration and other vocational rehabilitation services for any child who needs them, where such services are not available with reasonable promptness from another source.

R. Treitel, "Rehabilitation of the Disabled," *Social Security Survey of the Disabled: 1966*, U.S. Department of Health, Education and Welfare, Social Security Administration, Office of Research and Statistics, Report 12, September 1970. This is one example from a series of useful reports generated from the 1966 survey of disabled adults which covered the civilian noninstitutionalized population aged 18-64 in a national household sample. Rehabilitation services were broadly defined to include standard VR services plus services not delivered for a vocational objective such as physical therapy and training for leisure activity. The breakdown of data given that is most relevant to this study is for the 18-44 year olds. Of the 6,562,000 total disabled aged 18-44, 1,810,000 were so severely disabled that they were unable to work regularly or at all; 1,692,000 were occupationally disabled and could work regularly but not full time or at the same work as before they became disabled; and 3,060,000 had secondary work limitations that permitted them to work full time at the same type of job that they held before they became disabled. The percentage of the age 18-44 disabled who received services, and the percentage currently interested in receiving them are, respectively: all disabled, 17 and 17 percent; severely disabled, 18 and 24 percent; and occupationally disabled, 13 and 16 percent. For persons of all ages who received services, the VR agencies served only 19 percent.

and the Veterans Administration served 18 percent. Thus, the broad definition of rehabilitation used and the age breakdowns used make these survey results of less than high value to this handicapped youth research. Certain of the results are interesting and rather surprising, however; for example, "only 1 in 7 of the disabled expressed interest in obtaining rehabilitation services. Seventy percent of those who didn't try to get services didn't think they needed them or could be helped."

S. Z. Nagi, Social and Rehabilitation Services Survey, *Service Organizations and the Public: Research Plans*, Ohio State University, Columbus, Ohio, July 1972. This large, detailed, and comprehensive survey has two components: a survey of the adult general population, and a survey of welfare and rehabilitation recipients. Some purposes of the survey are to identify the epidemiological patterns of disability; to describe and explain the patterns of needs, demands, and utilization of services, and the results of the services; to identify target populations for the service programs included in the study; to describe and explain the experiences of applicants, clients, and former clients with service organizations (and vice versa); and to describe and explain the relationships among service organizations. Plans call for a cross-sectional United States population sample of over 6000 personal interviews. Plans also call for interviews with about 1500 to 2000 applicants for public assistance or vocational rehabilitation. The planned work will take place over a five-year period with some initial results available in late 1973.

U.S. Department of Health, Education and Welfare, *Rehabilitation of the Disabled in Fifty-One Countries*, Vocational Rehabilitation Administration, December 1964. This descriptive report provides overviews, each a few pages long, on rehabilitation programs in 51 countries throughout the world. It briefly describes the geography, economy, and population of the country, and its history in the rehabilitation field. Current public and private programs are summarized giving, if known, organizational structure, service delivery mechanisms, types of services offered, and number of handicapped persons served. This overview information is especially useful in identifying for further investigation countries that have implemented programs similar to those that the United States might consider adopting.

In nearly all countries, major efforts are being made by a variety of mechanisms, ranging from strong national control to heavy reliance on privately run programs, to provide vocational rehabilitation services to the handicapped. The report concludes that developments in various countries indicate a "general and pervasive" need for central planning and coordination of these services, and that countries are progressively moving toward total rehabilitation of the individual by providing a comprehensive package of services. Other countries with programs of the scope equal to that of the United States are said to include the United Kingdom, Sweden, Finland, and France.

R. W. Conley: *The Economics of Vocational Rehabilitation*, Johns Hopkins Press, Baltimore, 1965; and idem., "A Benefit-Cost Analysis of the Vocational Rehabilitation Program," *The Journal of Human Resources*, Vol. IV, No. 2, April 1969. No one has been more energetic or pioneering in applying benefit-cost analytic techniques to programs for the handicapped. His book cited above describes what an ideal benefit-cost study would be like, reviews the literature and problems associated with feasible studies in the VR area, and analyzes the VR program using

data from the early 1960s. In the journal article cited above, Dr. Conley extends the earlier evaluation using 1967 data and refines the methodological techniques used. He has also made an evaluation in the area of mental retardation.³¹

In his analysis of the VR program, Dr. Conley focuses on economic costs and benefits. He is about as sophisticated as one can be with available data, and clearly states his assumptions when making estimates. Using 1967 data, he estimates that for each dollar of the social cost of rehabilitation services, an increase in lifetime earnings of a little less than \$5 accrues (at a 4-percent discount rate on future increased earnings). He also estimates that "the increased taxes paid by the rehabilitants and the reduction in tax supported payments for their maintenance amount to perhaps as much as 25 percent of the total increase in earnings." Critical assumptions underlying those estimates relate to how one estimates what earnings would have been without rehabilitation, and what the employment record of the rehabilitant will be over his lifetime.

U.S. Department of Health, Education and Welfare, *Rehabilitation Facility Needs in the 1970s*, Rehabilitation Services Administration, Monograph #1. In 1968, the U.S. Rehabilitation Services Administration surveyed the states to obtain data on the need to improve existing rehabilitation facilities and to construct new ones. This national survey sought the results of facility planning that had been funded by grants under the VR Amendments of 1965. The work reported in this monograph is exemplary in that the Federal Government first expended funds for planning and data generation, and then systematically collected and disseminated the information.

Data are presented for each state on the number of new rehabilitation facilities needed by type and program emphasis, the estimated cost of such facilities, the number of existing facilities by type, and the estimated funds needed to improve existing facilities through June 30, 1971. In summary, the findings were as follows:

- 1829 new rehabilitation facilities, including 584 sheltered workshops, are immediately needed nationally.
- Estimated Federal funds required for the planning, construction, and initial staffing of new rehabilitation facilities total over \$282 million.
- 2656 existing rehabilitation facilities, including 1029 sheltered workshops, have been identified and studied.
- 1130 of these have known improvement needs (i.e., staff, equipment, technical consultation).
- Estimated Federal funds required to improve existing rehabilitation facilities total over \$41 million nationally.

A Follow-up Study of Closed Vocational Rehabilitation Cases, National Analysts, Inc., Philadelphia, Pennsylvania, for the U.S. Department of Health, Education and Welfare, April 1972. This report contains three components: (1) the results of a follow-up personal interview on about 4000 persons in six states who had

³¹ A preliminary report is contained in R. W. Conley, "An Assessment of the Economic and Non-Economic Costs and Benefits of Mental Retardation Programs," in J. S. Cohen et al., *Benefit-Cost Analysis for Mental Retardation Programs; Theoretical Considerations and a Model for Application*, Institute for the Study of Mental Retardation and Related Disabilities, Ann Arbor, Michigan, 1971. Conley's complete work will be published in mid-1973.

received VR services one, two, or three years prior to the cross-sectional survey; (2) a cost-benefit analysis of the services provided, utilizing basically the same method as Ronald W. Conley, but with data from the follow-up survey; and (3) an analysis of data known at time of client application, in an attempt to predict VR success.

The criteria of success used included the proportion of time an individual had been employed during a given period and the employment status of the person at the time of the interview. Forty-seven percent of rehabilitants worked without interruption in the twelve months following closure, and of this figure 29 percent did not work for pay at all. Only 19 percent of the nonrehabilitants worked the year without interruption, whereas 60 percent had no work during the year. Over the longer three-year period, the fraction continuously employed declined somewhat, while those not employed at all also declined. The average number of months that nonrehabilitants worked was about half or less than those for rehabilitants. Rehabilitants employed at the time of the interview totaled 57 and 54 percent, respectively, for one and three years following closure. The comparable figures for nonrehabilitants were 18 and 23 percent for one and three years following closure. For clients less than age 20 at acceptance, 93 percent of male rehabilitants and 82 percent of female rehabilitants were fully employed at the time of the interview.

The benefit-cost ratios calculated, using a 4-percent discount rate for future earnings, were 9.8 for all rehabilitants and 17.1 for rehabilitants less than 20 years of age.

Directory of Rehabilitation Facilities, Association of Rehabilitation Centers, Inc., Washington, D.C., August 1968. A descriptive directory of rehabilitation facilities is presented, by state, showing the type of services offered, the type and number of patients served by age, the capacity of the facility, and a breakdown of the number and type of professionals employed. The data were obtained through voluntary responses to a survey in 1967 and cover only about 500 of the more than 2500 existing facilities. A summary profile of the responding facilities is included. An up-to-date version of this directory for each state, containing data on a larger fraction of the facilities, would be useful to persons trying to match individual needs with services offered.

Ongoing Vocational Rehabilitation Evaluation Studies. Two major evaluation projects of the VR program are currently under way. F. C. Collignon and Michael B. Teitz, at the University of California, Berkeley, are conducting a comprehensive and multi-faceted series of evaluations that include benefit-cost analysis. Abt Associates, Inc., of Cambridge, Massachusetts, has conducted a survey and evaluation due for publication early in 1973.

L. E. Riley and S. Z. Nagi, *Disability in the United States: A Compendium of Data on Prevalence and Programs*, Division of Disability Research, College of Medicine, Ohio State University, Columbus, Ohio, 1970. This represents the best quality work in the class of publications whose purpose it is to compile available data on a subject. The subject in this case is the handicapped: incidence and distribution in the population, public and private programs, and occupations and facilities serving the handicapped. VR represents only a small portion of the scope of this report. The compendium of data is very comprehensive, and careful attention is given to specifying both original data sources and limitations in the quality of the information presented.

Blindness and Services to the Blind in the United States, Organization for Social and Technical Innovation, Inc., Cambridge, Massachusetts, June 1968; and D. A. Schon, "The Blindness System," *The Public Interest*, Number 18, Winter Issue, 1970. The report and article both describe the results of a year-long study conducted by the Organization for Social and Technical Innovation, Inc., for the National Institute of Neurological Diseases and Blindness, beginning in 1967. The study focused on a wide range of programs and services, including vocational rehabilitation, for visually handicapped persons of all ages. Services for the visually handicapped in the United States are described, some problems with the service system are identified, and suggestions for service improvement are offered.

Kenneth Trouern-Trend, *Blindness in the United States: Review of the Available Statistics with Estimates of the Prevalence of Blindness and Its Economic Impact*, The Travelers Research Center, Inc., Hartford, Connecticut, November 1968. The two-fold objective of this study is to review available statistics relevant to estimating the prevalence of blindness, and the "economic factors associated with it, as a basis for cost-benefit analysis of providing visual assistance for the blind by means of suitable devices or clinical procedures." Although time, effort, and data limitations allowed the author to do an excellent job of estimating the prevalence of blindness and to develop a good methodology for the cost-benefit analysis, they did not allow him to conduct an in-depth analysis. Still, this is one of the relatively rare cost-benefit analyses in the area of a physical handicap, and it contains a rather penetrating conceptual analysis. Most studies in this area estimate benefits by assuming that all individuals with some handicap are relieved of that burden. Such a computation does not reflect the facts that (1) the success of any intervention or service will not be perfect, and (2) treatments and services have costs that are likely to be an increasing function of the proportion of the population in need that is successfully treated or served.

Trouern-Trend attacks these problems in the context of blindness, using a model that considers (1) several defined groups of people, each with a specified type of blindness and other characteristics relevant for the success of some treatment or service; (2) a specified treatment or service; (3) the probability of success or the number of individuals in the given category that are likely to be successfully treated; and (4) the costs of the treatment. Given this information as well as data on such factors as life expectancy, employment and earnings, and costs of supporting non-working individuals, a benefit-cost analysis can be performed. The benefit side of Trouern-Trend's calculation consists of three elements: (1) The present value of the costs for supporting the defined handicapped group less the present value of the earnings of this group if they are unserved; (2) the present value of the support costs of those members in the group who were unsuccessfully treated; and (3) the present value of the expected lifetime earnings of the subgroup successfully treated. As Trouern-Trend points out, the use of economic earnings and service costs as the major components of the benefits generates a significant bias. The cost-benefit ratio will be higher for young, white males than for older, minority females. The implied policy bias is that resources should be concentrated on the former group; other policy objectives, however, may lead to a different resource allocation.

Trouern-Trend only partly applied his model. He was able to obtain data, albeit imperfect, on blindness characteristics. He used arbitrarily assumed probabilities of

success in his illustrative computations. Equally important, he did not specify the costs of treatment in his examples. In short, the model is relatively elegant but depends upon data on treatment costs and success probabilities that Trouern-Trend did not have time to collect and utilize. Consequently, his empirical results are merely suggestive.

Federal Programs for Young Children: Review and Recommendations, The Huron Institute, Cambridge, Massachusetts, 1972. This study focuses on the target population of young children, with special emphasis on the disadvantaged, including as a subset the physically and mentally handicapped. The charter of the research was to review existing data about child development and evaluate programs for children as a basis for recommendations for Federal program planning. In response to the great breadth of the charter, researchers at the Huron Institute compiled a massive wealth of information relating to programs and research serving children. This work was completed in late 1972, but as of this writing the final version was not publicly available, and hence we are unable to comment on specific recommendations made. Based on draft material we have seen, however, we commend the work as a valuable source of information and thoughtful recommendations.

6. EDUCATION OF THE HANDICAPPED

OVERVIEW AND SUMMARY

This section contains information about Federal programs and roles in the education of the handicapped, and Federal funds for such programs; data on special education programs in the states; a combined presentation of Federal and state expenditures for special education; a summary of survey responses from state education agencies; and a discussion of previous research and data availability.

To be able to compete successfully with his nonhandicapped counterparts in society, a handicapped person needs at least equal educational opportunities. Public support of special education is doubly important, since education in this country has traditionally been a public responsibility and, unlike in the health area for example, the parent of a handicapped child will find limited alternatives in the private sector for the education of his child. If private special education *is* available, there is no insurance plan or tax deduction to help defray the cost.

Because the learning process requires the coordination of physical and mental skills, many handicapping conditions become evident in the public school through formal school identification programs (e.g., vision and hearing screening) and informal methods (e.g., teacher observation). Once a handicapped child has been identified, medical or other services available in the public education system may be necessary, in addition to special educational assistance. Identification, counseling, and health-related programs are discussed in Sec. 8 of this report.

In 1971 special education programs in the United States assisted an estimated 3,046,000 physically or mentally handicapped youth under 22, or 6.6 percent of the public school enrollment. Total annual special education expenditures were an estimated \$2.7 billion, of which the Federal share was 12 percent, or \$315 million. Federal special education expenditures represented about 5 percent of the total Federal education budget. State and local expenditures earmarked as special education were also about 5 percent of total state and local education budgets.

A breakdown of Federal expenditures is shown in Table 6.1 for the three major types of programs: those for instruction of handicapped students (78.1 percent of expenditures); those designed to produce resources such as teachers and instructional materials (18.4 percent); and those sponsoring research (3.5 percent).

Total Federal and state and local expenditures by type of handicap are shown in Table 6.2. The mentally retarded receive the largest fraction of total expenditures—an estimated 45 percent—while speech impaired, emotionally disturbed, and learning disabled each receive 10 or 11 percent.

Table 6.1

SUMMARY OF FEDERAL PROGRAMS FOR EDUCATION OF THE HANDICAPPED

Program	FY 1972 Budget (\$ million)	Estimated Number of Youth Served (year)
Education	245.966	---
EHA-B	37.500	204,836 (1970)
ESEA-Title I		
Local Education Agencies	28.000	180,000 (1972)
89-313	56.381	107,698 (1970)
ESEA-Title III	20.100	134,047 (1971)
Headstart	33.384	37,900 (1973)
Vocational Education Act	38.384	221,342 (1972)
Higher Education Act	0.436	---
Federal Schools for Deaf		
Gallaudet College	7.888	1,583 (1971)
NTI for Deaf	2.907	395 (1971)
Kendall School	1.212	208 (1971)
Model Secondary School	2.524	100 (1972)
Special Target Groups		
Deaf-Blind Centers	7.500	2,300 (1971)
Early Education	7.500	2,000 (1971)
Learning Disabilities (EHA-G)	2.250	---
Instructional Support	57.906	---
Teaching Personnel		
EHA-D	35.145	---
Education Professions Develop-	6.100	---
ment Act		
Regional Resource Centers (EHA-C)	3.550	---
Media		
EHA-F	10.500	---
American Printing House for the		
Blind	1.580	---
Library of Congress	1.031	---
Research	10.994	---
Research (EHA-E)	10.994	---
Total	314.866	---

Priorities among age groups are essentially set by each state. The estimated expenditures by age group were preschool and elementary, 63 percent; secondary, 30 percent; and higher education, 7 percent.

The following subsection discusses each of the education programs sponsored by the Federal Government in terms of what they are intended to do and the function that the Federal Government has assumed in its sponsorship of the program. Much attention has been focused on the Federal role of stimulating innovation in the education of the handicapped. A reasonable allocation of program expenditures to Federal functions (see Table 6.3) showed that 44.2 percent of Federal expenditures for the handicapped were used for that stimulation function in FY 1972. Redistribution of resources from richer to poorer states was the major function of 9 percent of the funds, while basic support of services without a major attempt at redistribution of wealth accounted for 17.9 percent through support of state-operated or supported schools for the handicapped. The Federal Government also directly funds (28.9 percent of expenditures) certain services where economies of scale or externali-

Table 6.2
SUMMARY OF TOTAL SPECIAL EDUCATION EXPENDITURES AND NUMBER SERVED, BY TYPE OF HANDICAP^a

Type of Handicap	State & Local (\$ million) ^a	Federal (\$ million)	Total (\$ million)	Expenditures per Child Served (\$)	Total Number Served	Percent of Total Served
Mentally retarded, trainable	260.0	45.5	305.5	2064	148,000	4.9
Mentally retarded, educable	840.0	75.9	915.9	1217	752,000	24.7
Hard of hearing	55.0	13.6	68.6	1247	55,000	1.8
Deaf	91.0	42.5	133.5	4767	28,000	0.9
Speech impaired	251.0	21.8	272.8	197	1,383,000	45.4
Visually impaired	66.0	19.2	85.2	3043	28,000	0.9
Emotionally disturbed	258.0	35.0	293.0	1472	199,000	6.5
Crippled	210.0	10.0	220.0	1718	128,000	4.2
Learning disabled	250.0	32.1	282.1	1227	230,000	7.5
Other health impaired	84.0	19.2	103.2	1086	95,000	3.1
Total	2364.0	314.9	2678.9	879	3,046,000	100.0

^a See Table 6.9 and the subsections "Federal Programs, Roles, and Expenditures in Education of the Handicapped," "Special Education Programs in the States," and "State and Federal Expenditures for Education of the Handicapped" for data sources and methods of estimation.

Table 6.3

SUMMARY OF FY 1972 FEDERAL SPECIAL EDUCATION
EXPENDITURES, BY FUNCTION

<u>Function</u>	<u>Percent of Expenditures^a</u>
Redistribution of resources	9.0
Stimulation	44.2
Provision of services	
Economy of scale	11.1
Internalize externalities	17.8
Basic service support	17.9

^aSee the following subsection, "Federal Programs, Roles, and Expenditures in Education of the Handicapped," for methods of allocating funds by function.

ties, benefits accruing to all states, make it reasonable for the Federal rather than state governments to provide the services, e.g., higher education for the deaf, research, and teacher training.

The Federal program for aid in educating the handicapped has not grown within the framework of a comprehensive plan. Like other program areas with a long history of Federal involvement, this is a patchwork of loosely related activities. For example, two programs (ESEA-III and EHA-B) in practice may fund almost identical sorts of activities, yet are administered by different persons at the Federal and usually at the state level. Other programs were seemingly designed for the regular school population, and then a portion of their funds earmarked for the handicapped. Title III, the Vocational Education Act and Headstart are three Federal programs in which such a program design was followed. An accountability process of questionable quality was built into each of these programs to "ensure" that the earmarked funds actually flowed 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. The BEH, however, is responsible for managing only some 54 percent of the funds identified for special education of the handicapped in this section.

Since the Federal Government supplies only 12 percent of the total special education funds, the present Federal role is not a dominant one, but appears to be a hybrid mixture of the roles with primary emphasis on innovation and stimulation—the catalytic role.

The number of youth receiving special education services as a percentage of all handicapped youth needing those services varies considerably, depending on assumptions made about the incidence rate of the handicap in the population, and the age range of population that needs educational service. Using BEH estimates of the incidence rates, which are reasonable, and assuming that all handicapped youth aged 5-17 need some special education service, we estimate that 59 percent are served. If one assumes that all handicapped youth aged 0-21 need some special education assistance, then only 36 percent are presently being served.

Independent of the assumptions made, however, a large percentage of handicapped youth are unserved, and the percentage served varies markedly across the

states and across the various types of handicap. For example, estimated percentages of 5- to 17-year-old handicapped youth served vary across the states from less than 20 percent to more than 90 percent, and vary across the types of handicaps from less than 25 percent for the hard of hearing or emotionally disturbed up to more than 75 percent for the speech impaired. The mentally retarded, however, stand a good chance of receiving some educational service regardless of the state of residence. The minimum percentage of the retarded served in any state is 35 percent, but only thirteen states fall below 60 percent served.

The annual state and local special education expenditures per youth served average \$776, but vary from an average of \$170 for a speech-impaired youth up to \$3067 for a deaf youngster. The average for all handicaps except speech impairment is \$1271 per year. These data reported by the states understate the funds going to educate handicapped youth, since they probably represent special education "line items" in the state and local budgets, rather than total costs of educating a handicapped child. Services the handicapped child receives out of the regular education budget are probably not included (e.g., the \$170 for the speech-impaired may typically represent only the cost of a therapist). The reported variation in special education expenditures per youth served across the states for all handicaps is extreme: from \$213 in the lowest state to \$1705 in the highest spending state (excluding Alaska). The reported variation across states within a single handicap is even more striking. For example, the range for deafness is from less than \$100 to nearly \$10,000 per pupil per year. If all handicapped youth aged 5-17 were given the same quality special education services and at the same average cost as those presently being served, an estimated additional 2,109,000 youth would have to be served at an increase in the annual total special education budget of approximately \$2.5 billion. Any attempt to increase the percentage served cannot concentrate solely on reaching the population currently in school, but must extend the scope of the school program to reach age groups normally excluded from public schools, and to reach those who have dropped out or have never been admitted to public schools.

In an attempt to understand the variation among states in their special education expenditures per capita (aged 5-17), a simple regression model was formulated. The expenditure rate was regressed against measures of income, population density, and whether or not the state "mandated" special education. The analysis showed that the measure "per-capita income" was significantly related to the expenditure rate. "Mandating" legislation was related to the expenditure rate, but at a lower level of statistical significance (t -statistic = 1.6). Population density was unrelated.

As revealed in our survey, the problems that state governments face in educating the handicapped include the following: inadequate and uncertain funding, shortage of personnel, service problems associated with low incidence populations, lack of coordination among Federal programs, and lack of pre- and post-school programs.

Our review of research materials and data available to the special education planner shows that while a great amount gets published on special education, most of it deals with the classroom level rather than the program level. The decisionmaker in special education has little data on the effectiveness of special education on which to base his resource allocation decisions. We are not implying these programs are ineffective, but rather saying that little data exist to prove their effectiveness.

In summary, our main observations on special education programs are the following:

- State and local governments play the dominant role in special education, with the Federal Government supplying only 12 percent of the funds targeted specifically for handicapped youth. Federally supported programs are numerous and serve a wide variety of functions, the main one being innovation and stimulation, which accounts for about half the Federal expenditures. Because of this low level of financial involvement, the Legislative and Executive branches of the Federal Government do not have great leverage for inducing state and local governments to increase the quantity and quality of special education provided.
- Estimates of the percentage of handicapped youth unserved by any special education program vary widely depending on assumptions made, but all point to the same conclusion: A very large percentage of those needing special education are unserved.
- Extremely large variations in the percentage served exist across the states and across the types of handicaps. Large variations in expenditures per youth served also exist across the states within each type of handicap. The inequity with which the present total special education funds are expended is unmistakably clear.
- Data for planning at the state and Federal level are severely lacking. Estimates of the incidence of handicapping conditions are subject to great uncertainty. Estimates of the population served and the cost of state and local programs supported by Federal funds are made by state personnel on the basis of very little information. Little evaluation information is available relating special educational services to their impact on the lives of the handicapped.
- Expansion of special educational services to those now unserved will require much more than dollars. Incentives must be built in to alter the mix of types of handicaps served. As the mix of handicapped children changes, the mix of teacher skills and types of educational services must change. Identification programs will also be needed to find unserved youth in public schools, and those outside the present educational system.

FEDERAL PROGRAMS, ROLES, AND EXPENDITURES IN EDUCATION OF THE HANDICAPPED

In this subsection, we first describe Federal programs and the role that the Federal Government has assumed in sponsoring them, and then review the Federal share of the cost of these programs. More detailed data on the expenditures and pupils served in the states are presented in later subsections.

Federal Programs and Their Functions

A list of Federal programs aimed at educating handicapped youth is shown in Table 6.4. Based on the output of each program, they can be divided into three basic categories:

- Instruction of handicapped students.
- Production of resources in support of instruction.
- Research and development in education of the handicapped.

Table 6.4

FUNCTION OF FEDERAL PROGRAMS FOR EDUCATION OF THE HANDICAPPED

Program	Redistribution of Resources	Stimulation		Provision of Services		Basic Service Support
		Demonstration	Match	Economy of Scale	Internalize Externalities	
Education						
EHA-B		X				
ESEA-Title I						
Local Education Agencies 89-313	X					X
ESEA-Title III		X				
Headstart		X				
Vocational Education Act		X	X			
Higher Education Act	X					
Federal Schools for Deaf						
Gallaudet College				X		
NTI for Deaf				X		
Kendall School					X	
Model Secondary School					X	
Special Target Groups						
Deaf-Blind Centers			X	X		
Early Education		X	X			
Learning Disabilities (EHA-G)		X				
Instructional Support						
Teaching Personnel						
EHA-D					X	
Education Professions Development Act					X	
Regional Resource Centers (EHA-C)				X		
Media						
EHA-F				X		
American Printing House for the Blind				X		
Library of Congress				X		
Research						
Research (EHA-E)					X	

As our discussion will show, these categories cannot always be neatly separated in practice.

The programs are also classified by the function that the Federal Government is fulfilling in the particular program. Several Federal program functions are discussed in detail in Sec. 3, but for our discussion of education programs, the following four functions are most relevant:

- *Redistribution of resources* from one population group to another, e.g., from wealthy states to poorer states (or individuals). Two basic rationales for such redistributions are to increase the equity of service delivery and to increase the total productivity of society.
- *Stimulation* of state and local program development and investment in education of the handicapped. Demonstration projects, matching grants, and dissemi-

nation of information are attempts to improve and expand state and local programs by making effective service delivery mechanisms known, and by overcoming initial program start-up barriers such as lack of physical facilities. The Federal Government may match state and local fiscal effort with Federal grants. This lets the states buy more with their dollars and can increase the total amount spent on education of the handicapped. The Federal Government may also sponsor demonstration projects that permit state and local education agencies to see a program in operation before deciding to fund it themselves. Demonstrations also allow the Federal Government to pay initial investment costs; state and local governments then pay only annual operating costs. Demonstration projects thus lower both risk and cost to state and local governments of undertaking special education projects. Theoretically, this leads to more state and local dollars flowing to education than there would be without the Federal program.

- *Provision of services* that are more justifiable at the Federal than the state level because of economies of scale or significant externalities that can be internalized at the Federal level. First, there may be large economies of scale in the production of quality education for the handicapped, especially for low incidence population groups. It may be that these economies can be captured only at the Federal level. Second, Federal sponsorship of programs can internalize externalities, since certain investments by one state will have major benefits for another state. Research on educational techniques or the prevention of various types of handicaps, for example, would benefit every state, yet cost about the same whether paid for by the state or the Federal Government. If the state does not consider the benefits flowing to others (and there are no incentives to ensure that this would be the case), it will tend to underinvest in research. Only if the Federal Government operates the program are the costs and benefits to the nation as a whole likely to be considered in the decision.
- *Basic support* of special education services. In this function, the Federal Government assumes partial financial responsibility for some group of clients; the money is not given primarily to redistribute resources, stimulate state or local effort, or for other reasons previously discussed. One rationale often offered for Federal performance of this function is that a major unmet need for services exists, and state agencies have not filled that need because of budgetary problems. Another rationale is that the group needing services can exert pressure more effectively at the Federal level than it can at the state or local level. These groups may represent small minorities at the lower levels of government, but become a powerful lobby through organization at the Federal level. Handicapped persons and military veterans are examples of groups that may have more power at the Federal level than at the local level because of powerful national organizations.

The X marks in Table 6.4 describing the Federal function in each program indicate only the major one. Here again, assignment of roles and functions to programs cannot be made neatly. It should be realized, of course, that assignment of the roles is based on our opinions. We do not argue that any clear definition of Federal roles and functions was made when the authorizing legislation behind each program was approved.

Education of handicapped children is one focal point in the larger battle between the Executive and Legislative branches over the appropriate Federal role in public education.¹ Although this controversy has sharpened and clarified the present outlines of the Federal role, it has also made speculation about the forms that role might eventually take highly problematic.

The existing Federal role is somewhat ambiguous, and current imperatives issuing from several court decisions to ensure the right to an education for all handicapped children² and Executive Initiatives to institute Special Revenue Sharing for education of five categories of served populations (disadvantaged, handicapped, vocational education, assistance to federally impacted areas, and support services) to the tune of some \$2.5 billion may portend a significant Federal role change in the near future. It seems we presently have a hybrid but primarily Catalytic model situation that is being strongly pressured to become predominantly the Special Revenue Sharing model.

These roles are being carried out through an assortment of functional mechanisms, including research and development; seed money; demonstrations and experiments; direct investments in facilities, services, and personnel; and practically any other conceivable function that one might define. Special education for the handicapped is truly such a widely variegated class of activities that it practically defies generalization efforts.

Likewise, the rationales used to justify Federal involvement are multiple and variegated. Some definable programs are currently rationalized (whether implicitly or explicitly, it matters little) in terms of redistribution of resources arguments (e.g., ESEA, Title I, the Higher Education Act). Another cluster is most accurately labeled according to our characterization of the stimulator rationale (e.g., ESEA, Title III, Vocational Education Act, and Childhood Early Education). Some programs are primarily managed at the Federal level because of economies of scale considerations (e.g., Gallaudet College, media services, and the American Printing House for the Blind). Finally, still another cluster could be rationalized in terms of internalization of externalities (e.g., Model Secondary Schools for the Deaf, training teaching personnel under the Education of the Handicapped Act, and most research support).

In terms of dollar support justified under each category of rationalization, the picture is only slightly clearer. Approximately 44 percent—the largest share—of total Federal expenditures is classifiable under the stimulation category; some 9 percent under resource redistribution or balance wheel arguments; 20 percent under internalization of externalities; 18 percent as basic service support, all under ESEA-Title I; and 11 percent as economies of scale. The predominant functions being carried out using the most sizable or stimulation rationale are demonstrations and experiments and the provision of seed money as parts of the Education for the Handicapped Act (Title VI-B), the ESEA-Title III, and the Vocational Education Act.

¹ See Karen DeWitt, "Education Report/Handicapped School Children Enmeshed in Debate on Federal Role in Education," *National Journal*, Vol. 5, No. 6, February 10, 1972, pp. 199-205.

² Taken primarily from the equal protection provision of the 14th Amendment to the Constitution. The key court case was a class action successfully brought in Pennsylvania in 1971 (*Pennsylvania Association for Retarded Children vs Commonwealth of Pennsylvania*), determining that the state is responsible for providing a free education to all children, even if they are excluded from the normal classroom. This case has been generalized to include all physically and mentally handicapped children in *Mills vs Board of Education of the District of Columbia*. Similar suits further expanding on the basic equal provision concept are pending in at least fifteen states, including California, Colorado, Michigan, and Maryland.

Basic service support arguments could possibly have less persuasive power and likelihood of success in the future than policies and programs rooted primarily in efforts to stimulate, to cash in on scale economies, and to internalize externalities. This is entirely consistent with our previous speculation on the newly emerging Federal role in special education as demonstrating a mix of predominantly Model III (Special Revenue Sharing, Plus) and Model IV (Catalytic—Innovation and Stimulation).

Programs for the Direct Education of Handicapped Students

Education of the Handicapped Act (EHA), Part B. Under the provisions of this act, grants are made to the states to support education of handicapped children through initiation, expansion, or improvement of programs at the preschool, elementary school, and secondary school levels. The stated purpose is to stimulate state and local investment in special education. This stimulation is attempted through the demonstration mechanism since there is no matching requirement to obtain Federal funds under this program. Grants are allocated to the states based on the number of children in a state between the ages of 3 and 21. In FY 1970 the program supported education for 204,836 youth.³

Elementary and Secondary Education Act (ESEA) Title I. Title I provides grants to local education agencies for the education of children from low-income families. These funds are used to expand and improve educational programs which contribute to meeting the special educational needs of educationally deprived children. Handicapped children can benefit from Title I in three different ways:

1. Handicapped children make up part of the educationally deprived population, and as such they can benefit from the increase in school resources as well as the normal children.

2. Title I can be used to provide special education services to handicapped children where such services are not mandated by state law. This is likely to occur in low income states, where such a mandate would cause an immediate financial problem. The number of handicapped youth receiving educational support under this "nonmandated" portion of Title I in FY 1972 was an estimated 180,000.⁴

3. Perhaps the largest impact of ESEA-Title I on the handicapped population comes through an amendment to that act, P.L. 89-313. Under Title I as originally enacted, schools supported or run directly by the state were not eligible for Title I grants. P.L. 89-313 amended the Title so that state schools could participate in Title I. An estimated 107,698 handicapped youth benefited under P.L. 89-313 provisions in FY 1970.⁵

The Federal Government plays two different roles in Title I. For the most part, it acts to redistribute resources in providing compensatory education to educationally deprived children. The argument for Title I is that some school districts do not have the financial resources to carry out compensatory education. The size of the Federal grant is based on the number of children between the ages of 5 and 17 who

³ U.S. Bureau of Education for the Handicapped, *Aid to the States Information System, National Report*, September 1971. (As of this writing, FY 1971 data are not available.)

⁴ U.S. Congress, House, Subcommittee of the Committee on Appropriations, *Hearings, Part 2, Office of Education and Special Institutions*, 92d Cong., 2d sess., 1972 (hereafter cited as *Hearings*), p. 271.

⁵ *Aid to States Information System*.

come from low income families (less than \$2000 per year in 1972), who receive Aid to Families with Dependent Children, and who are in institutions for the neglected or delinquent. The Federal Government shifts resources to where they are thought to be more effective, and to make the distribution of educational services more nearly equitable. Whether such increased effectiveness is being achieved is a widely debated subject, but outside the scope of this report.

It is difficult to interpret the Federal function in P.L. 89-313 as one of redistributing resources. The allocation to a state is equal to the average per capita expenditure on education in that state (or one-half the national average, whichever is more) multiplied by the number of eligible handicapped children in average daily attendance (ADA) in all eligible state-operated and state-supported schools. This formula obviously has some balance wheel effect. Since poor states tend to spend less on education per capita than rich states, they will receive more than half of their average expenditures because of the minimum floor set by the national average. Although poor states will get more as a percentage of current expenditures than rich states get on ADA, they will get less money in absolute terms than the rich states get per ADA.

The rationales generally offered for a strong Federal role in redistributing resources are based on both the large amount of resources necessary to operate an adequate program and the wide range of financial capability among the states. In programs serving large numbers of persons, such as welfare and compensatory education, both of these arguments have some credibility. However, in the case of state-operated institutions, there is more room for argument. In a relatively low per capita income state, such as Arkansas for example, only 4 percent of the state budget goes toward operating state-run institutions.⁶ The educational component of those expenditures would be much smaller than the 4 percent, of course. The point is, however, that the funds for these schools could be greatly increased without dramatically affecting the size of the total state budget. Under such circumstances the need for redistribution of resources from state to state is far from clear.

Neither is P.L. 89-313 a matching program that can be interpreted primarily as one of stimulation. The Federal Government bases its grants on the average expenditures spent on all education and not just education at state-operated schools. Since the budget of the state schools is small in comparison to the total amount spent on education, the state cannot effectively increase the size of its grant by increasing expenditures at the state-operated schools.

The P.L. 89-313 program primarily functions as basic support for services. In effect, the Federal Government is saying that it will pay each state approximately \$450 for each eligible handicapped child in average daily attendance at state-operated and state-supported schools. The Federal Government has not assumed a basic support role for the education of the handicapped in general, but only for the handicapped in state-operated and state-supported schools.

ESEA Title III—Supplemental Education Centers and Services, Guidance Counseling and Testing. This Title is intended to assist schools in the development and establishment of exemplary elementary and secondary school educational programs to serve as models for the regular school program. To ensure

⁶ Based on the 1970-71 Budget of the Arkansas School for the Blind, Arkansas School for the Deaf, and the Arkansas Children's Colony (mental retardation), taken from *State of Arkansas Budget Manual*, Little Rock, February 1971.

that part of the funds allocated under this program is spent for special education, states are required to spend at least 15 percent of their Title III allotment on education of the handicapped. The language of Title III makes clear that the Federal function is one of stimulation: "The Commissioner shall carry out a program . . . to stimulate and assist in the provision of vitally needed education services."⁷

This stimulation is only brought about by the demonstration effect since Title III money is not distributed on a matching basis.⁸ A reported total of at least 134,047 youth received a portion of their educational services under this program in FY 1971.⁹

Headstart—Economic Opportunity Act. A new provision in the legislation authorizing the Headstart program is that 10 percent of the nationwide enrollment opportunities should be reserved for handicapped children. This would result in an estimated¹⁰ 37,900 handicapped youth being served. The reservation of the number of positions, rather than the earmarking of money (as in Title III), is a new approach to diverting money for the handicapped. This assures more accountability because it is easier to count handicapped children than it is to calculate the amount of resources going to a particular group of children.

This reservation of places rather than funds introduces a new incentive structure for the Headstart Project Director. If handicapped children are more expensive to serve than normal children (for some specified level of service), then more than 10 percent of the funds will be going to handicapped children. If the number of children to be served and appropriations were to remain approximately constant, the quantity and/or quality of service received by the normal population within Headstart would decline.¹¹

The Project Director has several other choices. First, a probable course of action would be to accept children with only slight handicaps.¹² In such a case, cost differences between the handicapped population and the normal group may be minimal. Second, he may choose to offer the handicapped the same mix of services as the

⁷ U.S. Congress, House, Committee on Education and Labor, *Compilation of Federal Elementary and Secondary Education Legislation*, 92d Cong., 2d sess., 1970, p. 35.

⁸ The Title III allocation to each state is based on the following formula:

$$G(i) = 200,000 + \frac{.5(a - 10,000,000)k(i)}{\sum_{i=1}^{50} k(i)} + \frac{.5(a - 10,000,000)p(i)}{\sum_{i=1}^{50} p(i)}$$

where $G(i)$ = grant to the i th state,
 a = Title III appropriation,
 $k(i)$ = number of children between 5 and 17 residing in state i ,
 $p(i)$ = population of each state i .

This formula is an approximation since it excludes consideration of Puerto Rico, Indian children, the Pacific Trust Territories, and overseas schools operated by the Department of Defense. Such exclusions, however, lead to only a small error.

⁹ Compiled from 1972 Title III State Reports to the U.S. Office of Education. Five states (Kentucky, Maryland, Montana, New Hampshire, and Pennsylvania) and the District of Columbia are excluded from this total either because the state report was not available or was inadequately prepared. Program total excludes Texas, which was reported serving 375,000 or an average Title III per-pupil expenditure of \$2.37.

¹⁰ *Education Daily*, September 12, 1972, p. 5.

¹¹ Quality will decline as measured by dollars spent per normal enrollee. Whether quality as measured by an objective measure of program output will decline is not known.

¹² This course appears most probable since it costs the least, disrupts "normal operating procedures" the least, and since the practice of "creaming" or selecting the least handicapped for admittance to a government program appeared to be a phenomenon in several of the agencies visited during this study.

normal group. It is difficult to predict the outcome of this second alternative. While it may be beneficial to have some program as opposed to none, it would appear on its face to be far from optimal. Since the program has not yet started, no evidence on the actions of project directors with respect to this incentive structure can be measured. In the coming years, however, such reaction should be monitored to ensure that the handicapped are receiving reasonable net benefits from the Head-start Program.

Vocational Education Act of 1963 as Amended. The Vocational Education Act provides that 10 percent of the basic grant funds allocated to each state be spent on the handicapped. These funds are used to support the expansion of vocational education in high schools, state-operated schools for the handicapped, community colleges, area vocational schools, and other schools. Because the program requires a 50 percent matching with state funds, it must be considered a stimulator of local investment in vocational education. A total of 208,781 and 221,342 youth benefited from this program in FY 1971 and FY 1972, respectively.¹³

Higher Education Amendments of 1968 (P.L. 90-575). This act provides for grants to colleges and universities to assist them in developing programs for disadvantaged students. One qualifying criterion for being disadvantaged is having a physical handicap. A student may also be disadvantaged by reason of a deprived educational, cultural, or economic background. The Federal Government, whose function here is primarily to redistribute resources, is apparently attempting to correct underinvestment in education in early years that may have been due in part to the financially hard pressed nature of the local and state education agency serving the students in their early years.

Federally Sponsored Schools for the Deaf. The Federal Government's special interest in schools for the deaf is reflected in its sponsorship of four such schools. In the area of higher education the Federal Government sponsors Gallaudet College (P.L. 83-240), which provides an undergraduate and graduate program for the deaf, a graduate school program in the field of deafness, and adult education for deaf persons. It also operates the Kendall School for Deaf Children, a preschool program for very deaf young children, and the Model Secondary School for the Deaf (P.L. 89-694). This latter school not only provides basic education to its students, but is also a research laboratory in the methods of instructing the deaf. The National Technical Institute for the Deaf (P.L. 89-36), located at Rochester Institute of Technology, specializes in post-secondary school training of the deaf to prepare them for employment.

In support of Gallaudet College and the National Technical Institute for the Deaf, the Federal Government has in a sense nationalized higher education for the deaf in order to achieve economies of scale. These are the only schools of their kind in the country. The Federal Government has not precluded other levels of government from providing this service, but apparently there are not enough deaf persons at the state level to lower the average costs to a state agency to reasonable levels or to offer a quality diversified educational program at the state level. Support for the Kendall School and Model Secondary School can be justified by the externality

¹³ U.S. Department of Health, Education and Welfare, Office of Education, Bureau of Adult, Vocational and Technical Education, *Summary Data—Vocational Education, Fiscal Year 1971*, Vocational Education Information No. 1; and letter from Harold F. Duis, Program Support branch, DHEW/OE/BAVTE, to J. S. Kakalik, The Rand Corporation, May 9, 1973.

argument. Research into better practices in teaching the deaf obviously has payoffs to all states. This externality to a state may lead single states to underinvest in research, and necessitate Federal programs to correct this deficiency. In 1971 the number served at Gallaudet was 1583; at NTID, 399; and at the Kendall school, 208.¹⁴ The 1973 projected enrollment level at the Model Secondary School is 100.¹⁵

Special Target Groups. Three educational programs authorized under EHA-Parts C and G are aimed at either a specific disability or age group. One of these provides model centers for deaf-blind children. A recent increase in the prevalence of deaf-blind children (though still a very low incidence population) brought about in part by the rubella epidemic of 1964-65 left many children without access to educational services. Services were available to some of the deaf and some of the blind, but the sensorially multihandicapped add another dimension to the education process. The deaf-blind centers were an attempt to overcome this gap in service to a severely impaired handicapped group. An estimated total of 2300 were served in FY 1971.¹⁶ The low prevalence of the handicap made it difficult for many states to provide services to this handicapped group at a reasonable cost. By providing regional centers, the Federal Government is capturing the economies of scale in formulating a program for educating these children. In addition, the externalities of research benefits of this program may be large.

The Federal Government also sponsors a demonstration program of early education for handicapped children and will pay 90 percent of the cost of experimental preschool programs for handicapped youth. This program is stimulative in terms of both the demonstration and matching effect, and served 2000 youth in FY 1971.¹⁷

EHA-Part G provides model centers to meet the needs of children with specific learning disabilities. Some research and personnel training is also provided at these centers.

Programs To Provide Instructional Support

The Federal Government is involved in supporting programs that provide resources to the education process, as opposed to direct support of that process.

Teaching Personnel. Two Federal programs are aimed at increasing the supply of special education teachers. EHA-Part D develops personnel through graduate training, sponsors training for personnel presently engaged or preparing to engage in teaching the handicapped, and provides college fellowships to students pursuing a career in special education. The programs authorized under the Education Professions Development Act (P.L. 90-35) are similar to the personnel training component of the EHA. Under P.L. 90-35 both student fellowships and grants to colleges for program development are sponsored.

As mentioned earlier, Federal sponsorship of programs directed at increasing the supply of teaching personnel is an example of the recognition of the externalities involved in producing teachers. Highly trained teachers of the handicapped are mobile. If one state produces teachers who eventually migrate, they receive smaller

¹⁴ *Hearings*, pp. 1112, 1178.

¹⁵ *Ibid.*, p. 1135.

¹⁶ *Ibid.*, p. 420.

¹⁷ *Ibid.*, p. 422.

benefits for their investment. Federal sponsorship helps to offset this reduction in benefits by also reducing the cost of production. Most new special education professionals are trained in programs supported by the Federal Government. In FY 1970, 17,731 students finished training under programs supported by the U.S. Bureau of Education for the Handicapped.¹⁸

One additional program, EHA-C, sponsors regional resource centers that concentrate on developing curriculum to aid teaching personnel in the instruction of handicapped children. These centers also are partially involved in research and in training personnel.

Media. EHA-F makes available captioned films to the deaf, provides for a National Center of Educational Media and Materials for the Handicapped, and funds media-related research. The National Center and other depositories around the country can be of assistance to local school districts in supplementing their media inventory.

Another media program supported by the Federal Government is the American Printing House for the Blind (APHB). APHB manufactures books and other materials for use by the blind.

A third media program is run by the Library of Congress, which provides free loan books and magazines in Braille and on records for the blind and physically handicapped. This reading material is distributed to libraries throughout the country for circulation to individual readers. The Library of Congress also maintains the National Collections of Braille and recorded books to supplement titles deposited in the libraries. The program is reaching some 120,000 readers,¹⁹ but only about 12 percent of these, or 14,400, are 22 years of age or younger.²⁰ Federal involvement in each of these programs is called for because of the economies of scale that are available in the production of media.

Research Programs

A significant percentage of the money devoted to the handicapped can be classified as research. ESEA-Title III and EHA-Title VI-B are largely devoted to experimentation in alternative methods of educating the handicapped. For the purposes of this report, however, research is limited to those items that are termed research in the authorizing legislation.

The Federal role in research is based on the notion of internalizing externalities. That is, research has benefits for everyone, not just the persons performing the research. For example, research in Maryland on curriculum for teaching autistic children can have applicability to teaching children with the same handicapping condition in other states. The Federal Government in this case acts as a consortium of the states in performing the needed research to carry out effective special education programs.

¹⁸ Catalog of Federal Domestic Assistance, Section 13.451, "Handicapped Teacher Education" (update to 1972 issue), U.S. Office of Management and Budget.

¹⁹ Nelson Associates, Inc., *A Survey of Reader Characteristics, Reading Interests, and Equipment Preferences: A Study of Circulation Systems in Selected Regional Libraries*, Washington, D.C., 1969, p. 111.

²⁰ *Ibid.*, p. 3. (Linear interpolation was used to estimate the number classified in the 15-24 age bracket that were under 22.)

The only major Federal program devoted primarily to research for educating the handicapped is EHA-E, which provides for research grants and demonstration programs.

Federal Funds for Education of the Handicapped

Having briefly described Federal programs that are directly and indirectly related to educating the handicapped, we now examine the size of the Federal commitment to each program. First, the Federal program for education of the handicapped is put into perspective by estimating its total cost and then showing this cost as a percentage of Federal expenditures on education, state expenditures on special education, and total outlays for education. Second, Federal expenditures are broken down by the level of instruction—preschool, elementary, secondary, and higher education. Third, expenditures are shown by the function that the Federal Government is playing in the education process. Finally, Federal expenditures are shown by type of handicapping condition.

Expenditures for Education of the Handicapped. An estimate of Federal expenditures for educating the handicapped in FY 1972 is presented in Table 6.5. The total is approximately \$315 million, with 78.1 percent allocated to direct support of the education of handicapped children, 18.4 percent to support of instruction through teacher training and media services, and 3.5 percent to research.

These percentage breakdowns may be misleading unless the definitions of the categories used in this report are kept clear. For example, much of the innovative or demonstration expenditures could be classified as research rather than as an expenditure in direct support of education. They have not been defined as research expenditures because in our opinion their primary intent is to stimulate change and local investment in special education, as opposed to using the classroom as a laboratory to explore the fundamental processes of special education. The dearth of evaluation and dissemination of reports on many of these projects suggests a priori that the classification system used here is correct.

The relative magnitude of the Federal programs becomes clearer when we put the budget for the education of the handicapped into some sort of perspective. One relevant comparison is that between Federal funds for education of the handicapped and total funds for education in general. A definitional problem arises in attempting to estimate total Federal funds for education. For our purposes, we estimate the Federal total as just the sum of the budget of the Office of Education and the Headstart Program. The total appropriation for these two items in 1972 was \$6.2 billion.²¹ That means that only 5 percent of Federal funds spent on education went for education of the handicapped.

Federal expenditures also make up only a small part of the total expenditures on special education. The state and local contribution to special education has been estimated at approximately \$2.3 billion.²² This means that the Federal Government

²¹ OE Budget was taken from *Hearings*, p. 41. Headstart appropriation was taken from *Education Daily*, September 12, 1972.

²² These estimates were derived from the reports filed by the state under EHA-B. The reliability of the data is in great doubt. Many of the estimates were made by taking an estimate of the number of children of each disability receiving some sort of service and multiplying by the unit cost of delivering some service education to that particular handicapped group. These estimates were neither based on a census

Table 6.5
 FY 1972 FEDERAL FUNDS FOR EDUCATION OF THE HANDICAPPED
 (\$ million)

Program	Budget (Fiscal Year 1972)	Function				
		Redistri- bution of Resources	Provision of Services			Basic Service Support
			Stimu- lation	Economy of Scale	Inter- nalize Exter- nalities	
Education	245.966	---	---	---	---	---
EHA-B ^a	37.500	---	37.500	---	---	---
ESEA-Title I						
Local Education Agencies ^b	28.000	28.000	---	---	---	---
89-313 ^b	56.381	---	---	---	---	56.381
ESEA-Title III ^c	20.100	---	20.100	---	---	---
Headstart ^d	33.384	---	33.384	---	---	---
Vocational Education Act ^e	38.384	---	38.384	---	---	---
Higher Education Act ^f	0.436	0.436	---	---	---	---
Federal Schools for Deaf ^g						
Gallaudet College ^h	7.888	---	---	7.888	---	---
NTI for Deaf ⁱ	2.907	---	---	2.907	---	---
Kendall School ^h	1.212	---	---	---	1.212	---
Model Secondary School ^j	2.524	---	---	---	2.524	---
Special Target Groups						
Deaf-Blind Centers ^a	7.500	---	---	7.500	---	---
Early Education ^a	7.500	---	7.500	---	---	---
Learning Disabilities (EHA-G) ^a	2.250	---	2.250	---	---	---
Instructional Support	57.906	---	---	---	---	---
Teaching Personnel ^k						
EHA-D	35.145	---	---	---	35.145	---
Education Professions Develop- ment Act	6.100	---	---	---	6.100	---
Regional Resource Centers (EHA-C) ^a	3.550	---	---	3.550	---	---
Media						
EHA-F ^a	10.500	---	---	10.500	---	---
American Printing House for the Blind ^l	1.580	---	---	1.580	---	---
Library of Congress ^m	1.031	---	---	1.031	---	---
Research	10.994	---	---	---	---	---
Research (EHA-E) ⁿ	10.994	---	---	---	10.994	---
Total	314.866	28.436	139.110	34.956	55.975	56.381
Percent	100.0	9.0	44.2	11.1	17.8	17.9

^aU.S. Congress, House, Subcommittee of the Committee on Appropriations, *Hearings, Part 2, Office of Education and Special Institutions*, 92d Cong., 2d sess., 1972 (hereafter cited as *Hearings*), p. 403.

^b*Hearings*, p. 271.

^c"The Big Package for Education for the Handicapped," *American Education*, May 1972, p. 39.

^dOffice of Child Development Headstart Program--State Worksheets, as reported in *Education Daily*, September 12, 1972.

^e*Hearings*, p. 584. Ten percent of Vocational Education funds are earmarked for the handicapped.

^fAn estimate of the percentage of program funds under this Act that were received by the handicapped was not available for 1972. Therefore, the 1973 estimate (taken from *Hearings*, p. 245) was multiplied by the ratio of 1972 to 1973 program funds to obtain the estimates presented here. Estimates of the total program were obtained from U.S. Department of Health, Education and Welfare *Justifications of Appropriation Estimates for Committee on Appropriations, Fiscal Year 1973*, Vol. III, *Office of Education*, Department of Health, Education and Welfare, Washington, D.C., p. 220.

^gAll estimates exclude construction costs.

^h*Hearings*, p. 1162.

ⁱ*Hearings*, p. 1107.

^j*Hearings*, p. 1122.

^k*Hearings*, p. 403. Includes Teacher Education, Physical Education and Recreation Training, and Recruitment and Information components of EHA.

^l*Hearings*, p. 1065.

^mEstimate for the Library of Congress--Books for the Blind and Physically Handicapped program was obtained by multiplying the fraction of total readers under age 22 by the FY 1972 budget estimate in "Budget Justification: Library of Congress Division for the Blind and Physically Handicapped," mimeo., 1972.

ⁿ*Hearings*, p. 433.

is bearing 12 percent of the cost of special education. The Federal Government pays about 7 percent of the total national expenditures for elementary and secondary education.²³ Given the uncertainties in the numbers that have been used thus far in the analysis, it is only correct to say that the percentage of expenditures borne by the Federal Government in support of education of the handicapped must be considered small in comparison to the size of both the total Federal, and state and local special and regular education program expenditures.

Expenditures by Level of Instruction. As shown in Table 6.6, the emphasis of the Federal program for education of the handicapped is at the preschool and elementary level. Approximately 63 percent of Federal funds go to this level of instruction, with 30 percent to secondary education, and only about 7 percent to post-secondary or higher education. These are only approximate estimates, however, since budget or population breakdowns by age group were not available for some programs accounting for about one-third of the total expenditures. In such cases, the distribution among the levels of instruction was assumed to closely follow that of the EHA-B program. Using the same definition of Federal funds for all education as was used earlier, the percentages going to each level are 71.7 percent to elementary and secondary education; 26.2 percent to higher education; and 3.1 percent to funds unallocated by level of education. We note that the Federal Government spends a much larger percentage of its total funds for all education on higher education than it does for special education of the handicapped. Given the relatively large percentage of the handicapped who do not go on to college, this difference in emphasis appears reasonable.

Expenditures by Federal Function. The relatively small size of the Federal expenditures for education of the handicapped almost precludes several of the functions as viable alternatives. Given the high cost of special education, it would be impossible for the Federal Government to fulfill a major or basic service support function at current budget levels. Given the dispersion of both wealth and income in this country, it would take a larger commitment on the part of the Federal Government than at present to serve as an effective balance wheel through redistribution of resources.

Table 6.5 includes an estimate of the funds devoted to each function. In the table each program is identified with a primary individual function. Other secondary functions of each program may also be important if the Federal Government is performing a dual function. The largest percentage of funds goes to the role of stimulation (44 percent), which is in agreement with the pronouncement by the Bureau of Education for the Handicapped that Federal policy is to stimulate state and local participation in special education.²⁴ Provision of services to achieve economies of scale or to internalize externalities receives 11 and 18 percent of the funds, respectively. The balance wheel funds for redistribution of resources account for only 9 percent of the special education budget and are part of larger balance wheel programs where budget levels may make this role practical. The Federal Government provides basic service support to only a very specialized group—those in

of handicapped students nor a careful cost analysis of the resources actually flowing to the handicapped group. The estimate presented is also biased downward because it does not include state expenditures for teacher training as was done in the estimate of Federal expenditures.

²³ *Hearings*, p. 372.

²⁴ E. Martin, *Hearings*, p. 360.

Table 6.6

FEDERAL EDUCATION EXPENDITURES FOR THE HANDICAPPED,
BY LEVEL OF INSTRUCTION

Program	Preschool, Elementary	Secondary	Post- Secondary and Higher
Education			
EHA-B ^a	28.1	9.4	---
ESEA-Title I			
Local Education Agencies ^b	21.0	7.0	---
89-313 ^c	28.2	28.2	---
ESEA-Title III ^b	15.1	4.9	---
Headstart	33.4	---	---
Vocational Education Act	---	28.4	10.0
Higher Education Act	---	---	0.4
Federal Schools for Deaf			
Gallaudet College	---	---	7.9
NTI for Deaf	---	---	2.9
Kendall School	1.2	---	---
Model Secondary School	---	2.5	---
Special Target Groups			
Deaf-Blind Centers	7.5	---	---
Early Education	7.5	---	---
Learning Disabilities (EHA-G) ^e	2.3	---	---
Instructional Support			
Teaching Personnel			
EHA-D ^b	26.3	8.8	---
Education Professions Development Act ^b	4.6	1.5	---
Regional Resource Centers (EHA-C) ^b	3.6	---	---
Media			
EHA-F ^b	7.9	2.6	---
American Printing House for the Blind ^b	1.2	0.4	---
Library of Congress ^d	---	1.0	---
Research			
Research (EHA-E) ^b	11.0	---	---
Total	198.9	94.7	21.2
Percent	63.2	30.1	6.7

^aSeventy-five percent of those served in this program were in preschool or elementary school. It was assumed that expenditures were proportional to the number of students served. See Bureau of Education for the Handicapped, *FY 1970 National Report*, p. 102 of Title VI-A section.

^bNo reference could be found showing the age distribution of the recipients of the services provided in some programs accounting for about one-third of all expenditures, including this program. It was assumed that the expenditure pattern followed that of the handicapped population served under EHA-B.

^cApproximately 50 percent of those served are 12 years of age or younger. Since grants are based on Average Daily Attendance at the schools, Federal expenditures are assumed to be directly proportional to the number served in each age group. See *National Report*, p. 47, on Public Law 89-313.

^dOnly 4 percent of the readers in this program are under 12 years old. (See Nelson Associates, *A Survey of Reader Characteristics, Reading Interests, and Equipment Preferences: A Study of Circulation Systems in Selected Regional Libraries*, Washington, D.C., 1969, p. 3.) We assume nearly all funds went to secondary school students.

^eLearning disabilities are most pronounced among the very young. It was assumed that nearly all of the other centers served the same population.

state-operated or state-supported facilities for the handicapped—and this accounts for 18 percent of the special education budget. Even here, however, the size of the basic support grant is small in comparison with the total cost of operating most of these institutions, especially the residential ones. The grant is approximately \$450 per child while the typical per-student residential school cost is \$4,500 per year.²⁵

Expenditures by Type of Disability. The great bulk of Federal expenditures for education of the handicapped is not allocated on a categorical basis to any specific handicapped group. Table 6.7 presents an estimate of the amount of money that is specifically allocated to a disability; 92 percent is noncategorical aid.

Table 6.7

FEDERAL EXPENDITURES ON EDUCATION OF THE HANDICAPPED

Type of Handicap	Expenditures
Blind (American Printing House for the Blind)	\$ 1,580,000
Deaf (Federal Schools for the Deaf)	14,531,000
Deaf-Blind (Model Centers for the Deaf-Blind)	7,500,000
Learning disabled	2,250,000
Noncategorical for type of disability	289,005,000

When the money is not earmarked by the Federal Government, the state governments are allowed to spend according to their own preferences among disabilities—subject to Federal review, of course. Table 6.8 presents an estimate of how the funds are allocated among the various handicapping conditions for two Federal programs, EHA-B and P.L. 89-313.

The table shows that nearly half of the Federal funds for these two programs goes to the mentally retarded, split fairly evenly between the trainable and educable. Only 13.5 percent of the funds go to the emotionally disturbed, and there is some evidence that even this proportion is overestimated. In the states that were visited in the course of the study (Arkansas, California, Illinois, Massachusetts, and Wyoming), some of the emotionally disturbed—primarily adolescents—could be more accurately defined as socially maladjusted. It was also brought out in the interviews that many of these children were multihandicapped, but not reported as such. For example, many of the children in residential schools for the blind or deaf may also be mentally retarded. Therefore, the clear distinctions among handicapped groups shown in Table 6.8 are somewhat illusory.

The distribution of funds to handicapped groups does not necessarily reflect the number of children served in each group. In the EHA-B program, large differences in the number served for a given level of expenditure can be expected because of the large variances in the unit service costs among handicapping conditions. Under the institution program (P.L. 89-313), Federal funds are based on a school's ADA. Vari-

²⁵ See R. A. Rossmiller, James Hale, and Lloyd Frohreich, *Educational Programs for Exceptional Children: Resource Configurations and Cost*, University of Wisconsin, Madison, Wisconsin, 1970, for a discussion of residential school costs.

Table 6.8

DISTRIBUTION OF FEDERAL EXPENDITURES FOR EHA-B AND
P.L. 89-313 BY HANDICAPPING CONDITION^a

Type of Handicap	EHA-B	P.L. 89-313	Total
Mentally retarded, trainable	10.0	39.5	26.3
Mentally retarded, educable	29.3	13.8	20.8
Hard of hearing	5.6	1.0	3.1
Deaf	6.4	16.6	12.0
Speech impaired	9.1	1.1	4.7
Visually impaired	4.4	6.4	5.5
Emotionally disturbed	11.4	15.1	13.5
Crippled	3.5	3.3	3.3
Learning disabled	12.6	0.9	6.1
Other health impaired	7.7	2.3	4.7
Total	100.0	100.0	100.0

^a Estimates are from the Bureau of Education for the Handicapped, *Aid to States, Branch Information System, National Report, EHA-B, FY 1970, p. 8; and 89-313, p. 9.*

ances in the number served under this program come about because of the difference in the average length of stay at a school experienced by each handicapped group. A trainable mentally retarded person, for example, is likely to stay at an institution for a whole academic year. In this case, ADA and the number served are likely to be nearly identical. An emotionally disturbed child is less likely to stay for an extended period. He could receive services and then be returned to the regular school system. One school for the emotionally disturbed visited during the study, for example, had an ADA of 14, but served over 200 children during the year. The Federal formula for distributing funds to the states under P.L. 89-313 creates an incentive for longer treatment periods as opposed to intensive care. The size of this impact on the type of treatment or its effect on the children has not been measured.

SPECIAL EDUCATION PROGRAMS IN THE STATES

Resources for education of the handicapped are largely state and local. Operation of institutions for mentally retarded, blind, and deaf youth are an integral part of education programs in most of the states. In terms of money and children served, however, the larger state program is one of direct transfer of funds to local school districts or private schools for operation of special education programs.

This subsection describes the programs sponsored by the states in terms of the number of people affected and the amount of funds devoted to each program. From the standpoint of Federal policy, however, it is perhaps more important to attempt to determine why state programs are the way they are. That is, we will examine the determinants of spending on special education. If some states spend more, because of income, for example, there may be a priori evidence for the need of Federal

redistribution of resources. If states are spending less because special education is not mandated, the call for Federal expenditures is less clear.

To compile this description of programs, we used three different data collection methods. First, we visited five states to obtain background information on a cross section of state programs. Second, we sent a questionnaire to all the states, requesting information on their programs for education of the handicapped (see Appendix D). Third, we used reports filed with the Federal Government by the State Education Agencies on their programs.

Although the questionnaires provided a large volume of information, they were not an entirely satisfactory method of gathering information. Some states supplied excellent responses, but many did not. An accurate national picture could not be compiled from the returned questionnaires. Therefore, those data were used mainly as checks against information supplied to the Federal Government, and for examples of different kinds of programs that exist in the states. These latter data should prove useful in preparing a subsequent Rand report on hearing and vision programs. In all but a few cases the states did not have any more evaluation information than that required on Federal reporting forms, so using Federal data did not mean a great loss of information. Detailed data on the resource configuration and effectiveness of individual programs are generally not available at the state level, and would have to be obtained by surveying individual districts. Such a survey is outside the scope of this report, but is included in other work being sponsored by the Bureau of Education for the Handicapped.²⁶

State and Local Expenditures

One difficulty in analyzing program expenditures for educating the handicapped is the lack of reliable data. Much of special education is intermingled with the regular school program, making it difficult to identify the additional cost of special education. Moreover, in the residential schools, where the handicapped are isolated from the regular program, only a fraction of the total cost goes for instruction. This fraction cannot be easily identified in the financial records of the schools.²⁷

Estimates of expenditures on special education, then, are not very reliable and will vary from source to source depending on the assumptions made about allocating cost between the regular and the special programs. Table 6.9 presents estimates of state and local spending on education of the handicapped that were prepared by personnel in the various state departments of education.²⁸ While the estimates are not precise, they are valuable in two ways. First, they give an order of magnitude picture of the total amount of funds being devoted to education of the handicapped. This is useful in assessing the size of the program against the size of the problem.

²⁶ A report titled "Evaluation of an Aid to States Program for Education of Handicapped Children" is being prepared by Exotech Systems, Inc. While it would have been of great benefit to draw on this research, it was not available in time for inclusion in this report.

²⁷ See Rossmiller, Hale, and Frohreich, p. 41.

²⁸ These estimates were taken from the state plans submitted in 1972 by each state to the Bureau of Education for the Handicapped. From discussions with personnel in various states responsible for making these estimates, it became clear that their methodology could not lead to accurate estimates. For example, one state estimated the cost by multiplying the number of handicapped served by \$1000, almost regardless of the disability. In other cases it appears that when the State Education Agency was not responsible for residential schools, the costs of these schools were excluded from the estimates. The analysis presented in this section should be interpreted with this data reliability problem well in mind.

Table 6.9

ESTIMATED STATE AND LOCAL EXPENDITURES ON EDUCATION OF THE HANDICAPPED, 1972-73^a
(\$ thousand)

State	Mentally Retarded		Hard of Hearing	Deaf	Speech Impaired	Visually Impaired	Emotionally Disturbed	Crippled	Learning Disabled	Other Health Impaired	Total
	Trainable	Educable									
Alabama	960	7,539	300	581	840	161	454	322	504	427	12,088
Alaska	275	2,244	381	105	190	84	402	85	1,058	127	4,954
Arizona	1,085	7,906	120	0	609	165	1,026	209	483	803	12,408
Arkansas	1,091	1,609	0	1,304	46	923	70	115	142	31	5,332
California	27,560	62,800	14,700	10,500	15,225	7,009	0	81,900	78,750	0	298,435
Colorado ^b	1,585	5,518	0	0	2,046	341	1,876	1,183	4,996	2,508	20,067
Connecticut	5,551	8,416	2,820	0	3,282	1,157	6,770	3,255	8,777	0	40,278
Delaware	1,744	2,524	13	475	540	0	1,228	540	1,552	1,593	9,805
Florida	5,008	27,728	2,160	2,480	5,040	1,120	9,040	4,432	6,256	0	71,520
Georgia	2,220	11,412	834	1,745	11,142	3,915	4,762	0	2,840	3,227	42,475
Hawaii	1,358	2,821	95	607	65	96	493	383	1,221	224	7,367
Idaho	430	1,542	10	5	518	7	0	11	622	0	3,791
Illinois	8,805	47,295	1,365	11,850	18,195	2,430	23,385	12,675	15,585	5,325	174,585
Indiana	5,669	10,399	143	1,432	3,798	1,362	983	717	267	118	28,617
Iowa	1,750	7,320	1,080	360	4,270	380	2,875	655	1,320	778	24,565
Kansas	1,186	6,849	399	0	1,917	185	1,165	1,082	738	554	15,876
Kentucky	1,312	8,074	619	258	4,451	147	889	1,829	1,252	0	18,935
Louisiana	650	5,000	100	40	1,500	70	600	140	850	400	10,850
Maine	560	740	26	805	297	202	173	251	334	108	3,713
Maryland	3,165	4,236	633	462	1,117	448	1,307	438	6,893	4,987	24,616
Massachusetts	3,421	19,189	469	4,267	3,489	1,942	12,402	3,489	6,763	0	55,435
Michigan	27,397	46,044	5,296	6,920	17,253	4,298	9,893	8,715	0	0	153,896
Minnesota	6,408	15,162	0	2,957	4,255	1,075	19,800	1,507	19,800	130	61,547
Mississippi	553	5,010	121	806	506	319	28	303	373	2	8,023
Missouri	0	19,877	652	0	33,751	129	808	712	912	1,162	58,253
Montana	500	1,170	145	300	1,525	250	100	160	0	450	4,700
Nebraska	2,468	6,106	269	1,078	11,939	613	897	526	155	0	26,624
Nevada	375	1,697	125	62	500	50	1,062	250	0	0	4,247
New Hampshire	1,288	2,724	118	979	550	211	1,181	75	2,034	312	9,476
New Jersey	5,544	12,600	840	1,932	8,400	2,184	9,072	756	5,292	6,132	84,000
New Mexico	1,040	4,131	67	132	1,490	192	276	112	562	135	8,562
New York	42,123	139,557	4,399	15,666	14,832	12,889	97,744	44,170	0	15,309	403,650
North Carolina	2,519	17,054	2,769	0	3,007	2,415	1,391	673	762	583	31,316
North Dakota	224	1,155	19	0	733	40	154	643	133	49	3,152
Ohio ^c	29,400	97,200	0	7,000	16,200	2,400	0	5,000	24,400	7,800	174,200
Oklahoma	705	5,163	172	37	1,098	255	187	112	2,347	187	10,797
Oregon	1,697	4,800	440	412	1,808	1,919	706	390	1,200	616	12,239
Pennsylvania	13,193	50,862	1,336	1,518	13,524	2,899	5,566	6,287	0	5,692	100,879
Rhode Island	1,300	1,800	1,400	0	720	300	1,320	150	3,800	100	10,890
South Carolina	779	8,761	227	100	1,206	198	998	293	681	0	13,698
South Dakota	250	1,500	700	500	200	400	200	900	250	75	4,375
Tennessee	2,707	11,625	350	150	1,900	275	975	2,970	2,700	3,600	28,452
Texas	6,834	32,085	1,375	1,525	5,969	2,114	5,072	2,933	16,918	10,449	85,277
Utah	1,680	3,546	125	235	1,682	97	1,668	166	4,769	0	14,348
Vermont	425	1,044	206	253	192	105	217	349	299	98	3,190
Virginia	3,968	28,939	1,752	0	2,370	0	2,551	846	1,000	1,170	47,755
Washington	3,187	6,728	442	609	2,605	254	2,684	551	991	1,053	30,057
West Virginia	583	3,166	122	19	605	26	24	102	26	168	4,834
Wisconsin	7,670	2,815	1,610	3,718	6,441	3,275	4,567	2,015	2,205	652	64,509
Wyoming	240	1,029	31	186	373	73	192	38	544	20	3,256
D.C.	3,190	1,591	826	557	1,104	328	1,994	817	270	1,037	11,919
Total	260,000	840,000	55,000	91,000	251,000	66,000	258,000	210,000	250,000	84,000	2,564,000
Percent	11	35	2	4	11	3	11	8	11	4	100

NOTE: Column totals do not add to the United States total. When costs are shared among disabilities, they are listed in the "more than one" category on the Federal reporting form. Costs in this category were arbitrarily distributed among the disability totals in proportion to the total state and local expenditures for that disability.

^aThese statistics were compiled from *Description of Projected Activities for Fiscal Year 1973 for the Education of the Handicapped*, an annual report submitted to the Bureau of Education for the Handicapped by the fifty states under EHA-B. Completed forms from two states were not available.

^bColorado did not break down its total expenditures by disability. It was assumed that 1972-73 expenditures followed the same pattern as in 1968-69. All 1968-69 data were obtained from *Summary Statistics-Expenditures, FY 1968*, State-Federal Information Clearinghouse for Exceptional Children, Arlington, Va.

^cOhio reported only state expenditures. It was estimated that state expenditures were 50 percent of the total, as that percentage is typical of the region.

Second, these figures show the distribution of funds among handicapping conditions, thus enabling the planner to see where funds are going and to locate any apparent gaps in service in a particular state or nationwide.

The table shows that, of the total \$2,364,000,000 expended, a large percentage of state and local funds goes for education of the mentally retarded. Approximately one billion dollars are spent by these levels of government on both the trainable and educable mentally retarded. In other terms, 46 percent of the state and local effort, as measured by dollars expended, is going to the mentally retarded. The emotionally disturbed receive 11 percent of state and local funds. The speech impaired, learning disabled, and crippled groups each receive between 8 and 11 percent of the funds.

Number of Children Receiving Educational Services

The total number of students served is also a measure of the size of the program, and the number served as a percentage of those who require special education services is a measure of the gaps in service that may exist in particular states or in particular handicapping conditions.

Estimates of the total numbers served, by handicap, are presented in Table 6.10. The total number of handicapped children receiving service is estimated at 3.046 million, or 6.6 percent of the total enrollment in publicly supported elementary and secondary schools.²⁹

Figures on total enrollment for special education service are more revealing when they are shown as the number receiving service as a percentage of those who require service. Wholly reliable estimates of the size of the handicapped youth population are not available. For our purposes, however, it seems sufficient to use the estimates published by the Bureau of Education for the Handicapped. The incidence rates shown in Table 6.11 for school age youth were used in determining the number of handicapped children to be served. The incidence rate for all handicaps combined is 10.1 percent.

These particular estimates are low compared with some of the percentages used by the states to estimate the number needing service. Compelling evidence of the state-by-state variation in the definitions of various types of handicaps or of variations in the actual incidence rates is shown in Table 6.12, which lists the percentage served by state and by disability. The table shows too many cases of over 100 percent of the population being served for the definitions and incidence levels to be consistent across the states. An example would be separating hard-of-hearing and deaf children by different definitions.³⁰ From the data in Table 6.12, from the site visits taken during this study, and from the state survey, it appears that the percentage that are learning disabled and emotionally disturbed may be seriously under-

²⁹ K. A. Simon and W. V. Grant, *Digest of Educational Statistics*, U.S. Department of Health, Education and Welfare, DHEW Publication No. (OE) 72-45, 1971, p. 24.

³⁰ It could also be argued that the states are overestimating the number actually served. In one state, for example, the estimate was derived by multiplying the number of special education classes offered by the maximum permissible class size. This would lead to an upward bias in the estimates. There is no evidence, however, that this was just an isolated example. Some states combined their hard of hearing and deaf into one category. This gives the impression that they are serving a high percentage of one of the disabilities and zero percentage of the other. This same phenomenon occurs with the learning disabled, retarded, and the emotionally disturbed. The reader is advised that some of these coverages of over 100 percent are due to differences in classification.

Table 6.10
HANDICAPPED CHILDREN RECEIVING EDUCATIONAL SERVICE, BY DISABILITY

State	Mentally Retarded		Hard of Hearing	Deaf	Speech Impaired	Visually Impaired	Emotionally Disturbed	Crippled	Learning Disabled	Other Health Impaired	Total
	Trainable	Educable									
Alabama	2,208	13,884	347	777	8,550	426	616	452	620	540	28,420
Alaska	140	900	160	50	70	35	166	40	400	50	2,011
Arizona	952	6,153	60	0	6,090	61	799	163	376	473	15,127
Arkansas	1,800	7,377	0	342	5,010	224	329	146	845	357	16,430
California	11,000	47,000	3,000	3,000	130,000	2,500	0	58,000	60,000	0	313,900
Colorado	0	8,584	1,716	451	23,184	233	6,241	533	0	1,250	42,192
Connecticut	2,962	5,260	1,573	0	13,033	464	9,044	2,424	9,501	0	44,261
Delaware	650	2,800	8	155	4,000	95	910	200	920	580	10,318
Florida	3,450	26,000	11,410	1,400	33,590	1,050	7,500	7,000	9,000	0	100,400
Georgia	3,683	31,666	1,085	630	28,232	1,100	3,479	0	2,557	4,108	76,540
Hawaii	733	2,409	152	176	3,960	51	193	155	1,339	100	9,268
Idaho	492	1,700	53	109	4,786	80	0	32	2,908	0	10,160
Illinois	7,040	37,840	9,100	2,480	97,000	1,617	26,510	7,600	12,463	5,320	206,970
Indiana	5,420	18,968	200	927	48,616	374	745	402	190	106	75,948
Iowa	1,450	7,883	430	70	20,414	280	9,464	854	1,400	970	43,215
Kansas	945	7,735	256	0	16,000	180	1,300	770	1,170	1,300	29,656
Kentucky	1,464	13,560	1,040	288	19,000	143	850	2,044	984	0	39,373
Louisiana	1,000	13,500	300	100	32,000	150	1,000	200	1,700	1,000	50,950
Maine	665	2,900	98	336	3,700	283	320	405	800	102	9,609
Maryland	3,165	21,180	633	462	22,435	448	1,307	438	6,893	4,987	61,948
Massachusetts	1,969	12,106	1,087	1,377	32,934	730	3,345	5,300	16,480	0	75,528
Michigan	11,522	42,393	2,399	828	91,488	1,818	6,181	7,539	0	0	164,168
Minnesota	4,284	12,500	0	1,200	28,560	400	27,500	500	0	400	75,344
Mississippi	886	8,623	118	310	9,556	192	74	580	528	60	20,927
Missouri	0	19,877	652	0	33,751	129	808	712	912	1,162	58,003
Montana	510	1,700	53	60	3,000	103	600	750	1,733	45	8,554
Nebraska	2,240	6,043	281	305	17,047	246	913	378	1,302	136	28,891
Nevada	300	1,600	70	30	2,800	50	950	200	0	0	6,000
New Hampshire	619	1,999	263	213	5,050	108	463	50	1,304	244	10,313
New Jersey	6,043	20,561	691	1,654	61,023	1,875	26,274	1,178	5,748	24,625	149,772
New Mexico	1,040	4,590	75	265	2,980	385	276	125	625	150	10,511
New York	12,961	49,842	3,666	2,984	118,658	3,069	27,927	11,938	0	5,670	236,715
North Carolina	3,293	38,000	1,645	0	34,000	1,300	2,000	515	2,500	600	83,853
North Dakota	180	1,240	12	0	4,500	60	1,217	115	1,117	160	8,601
Ohio	14,760	53,239	0	2,436	93,035	1,089	0	1,650	18,645	6,576	191,430
Oklahoma	1,243	11,013	186	462	13,597	157	180	158	5,325	1,511	33,832
Oregon	887	4,670	325	398	14,500	250	650	444	7,000	700	29,824
Pennsylvania	6,200	43,233	1,500	600	80,500	2,050	2,200	2,187	0	1,980	140,450
Rhode Island	300	2,500	4,200	0	7,200	281	600	150	3,800	300	19,331
South Carolina	1,200	20,500	830	170	19,000	600	8,000	1,250	2,000	0	53,550
South Dakota	600	2,000	150	150	5,000	150	400	300	3,000	150	11,900
Tennessee	2,850	15,500	350	150	20,000	275	650	3,300	2,700	4,800	50,575
Texas	10,996	44,221	1,830	910	85,683	1,879	6,881	4,052	24,291	15,467	196,210
Utah	1,293	3,258	259	284	9,928	155	1,293	103	9,282	0	25,855
Vermont	313	1,181	236	87	1,440	86	430	72	1,049	300	5,194
Virginia	2,310	16,845	1,020	0	17,775	0	1,485	1,092	2,500	4,497	47,524
Washington	2,895	10,284	349	412	2,278	245	4,054	509	2,599	1,061	24,686
West Virginia	900	6,525	200	30	8,000	37	45	100	45	198	16,180
Wisconsin	3,985	15,474	676	377	32,352	436	1,580	432	851	2,433	58,596
Wyoming	150	710	65	49	2,150	165	120	280	620	300	4,609
D.C.	1,476	2,177	283	191	5,630	113	756	230	128	292	11,276
Total	148,000	752,000	55,000	28,000	1,383,000	28,000	199,000	128,000	230,000	95,000	3,046,000
Percent	4.5	24.9	1.8	1.0	45.4	0.9	6.5	4.2	7.5	3.2	100.0

SOURCE: Estimated 1972-73 students to be served from *Description of Projected Activities for FY 1973 for the Education of Handicapped Children*.

Table 6.11

INCIDENCE RATES FOR HANDICAPS

(In percent)

Speech impaired	3.5
Emotionally disturbed	2.0
Mentally retarded	2.3
Learning disabled	1.0
Hard of hearing	0.5
Deaf	0.075
Crippled or other health impaired	0.5
Visually impaired	0.1
Multihandicapped	0.06

SOURCE: *Short Term Analysis Issue in Education for the Handicapped*, prepared by the Office of Program Planning and Evaluation, Bureau of Education for the Handicapped, and Exotech Systems, Inc., November 1971.

estimated. Other incidence estimates for these are 3 percent emotionally disturbed and 5 percent learning disabled.³¹ If these latter estimates were used in the calculations, the percentage served of all handicaps across the country drops from 59 to 39 percent. Depending on the incidence levels, then, one can get a vastly different picture about how well the country is doing in meeting the educational needs of the handicapped.

The percentage served also depends on the assumptions about the proper base population to use. It could be argued that the base population should be the age cohort from 0-21. Certain types of handicapped children below the age of 5 need special educational services, and hence should be included in order to estimate those still needing service. Another line of reasoning is that the schools can only serve those who attend. Applying the handicapped incidence rates to the school population is one way of estimating how many handicapped children are in the regular school system and are not receiving special educational services, but are receiving normal instruction.³²

Using public school attendance population as a base also eliminates the bias introduced by the implicit assumption, which is made when general population data in an age range are used as a base, that those not served in the public schools are not served at all. Table 6.13 shows the percentage served for various base populations. The size of the public school population is measured in three ways—enroll-

³¹ Higher incidence rates than those used in this report are being reported by some states in their estimates of the size of the handicapped population. (See *Description of State Special Education Programs, FY 73*, submitted to the Bureau of Education for the Handicapped, U.S. Department of Health, Education and Welfare.) Nebraska estimates that 5 percent are emotionally disturbed and 7 percent are learning disabled. North Dakota uses 3 percent emotionally disturbed and 5 percent learning disabled. One study reported finding the use of incidence rates up to 20 percent for the learning disabled (M. Fleischmann, *Report of the New York State Commission on the Quality, Cost and Financing of Elementary and Secondary Education*, Vol. II, Albany, N.Y., 1972, p. 9.44). There are also lower estimates of incidence, as low as 0.05 percent for emotionally disturbed and 0.5 percent for the learning disabled (Rossmiller, Hale, and Frohreich, p. 121).

³² The implicit assumption in this estimation method is that the incidence rates are the same for the school population as they are for the general population.

Table 6.12

ESTIMATED PERCENT OF HANDICAPPED SERVED BY SPECIAL EDUCATION PROGRAMS, 1972-73

State	Mentally Retarded	Hard of Hearing	Deaf	Speech Impaired	Visually Impaired	Emotionally Disturbed	Crippled and Other	Learning Disabled	Total All Handicaps
Alabama	75.03	7.44	111.10	26.20	45.68	3.30	21.28	6.65	30.55
Alaska	41.95	29.69	61.85	1.86	32.47	7.70	16.70	37.11	18.70
Arizona	63.65	2.47	0.00	35.85	12.57	8.23	26.21	7.75	31.25
Arkansas	80.29	0.00	91.76	28.80	45.07	3.31	20.24	17.00	33.14
California	50.47	12.02	80.11	74.39	50.07	0.00	232.31	120.16	63.02
Colorado	63.51	58.40	102.33	112.72	39.65	53.10	60.68	0.00	71.98
Connecticut	46.58	41.00	0.00	48.52	60.46	58.93	63.17	123.81	57.82
Delaware	100.92	1.08	139.05	76.89	63.92	30.61	104.96	61.90	69.60
Florida	79.64	141.93	116.10	59.69	65.30	23.32	87.07	55.98	62.60
Georgia	125.71	17.75	68.71	65.98	89.97	14.23	67.20	20.91	62.76
Hawaii	67.02	14.92	115.14	55.51	25.02	4.73	25.02	65.70	45.59
Idaho	47.80	5.32	72.89	68.58	40.12	0.00	3.21	145.85	51.08
Illinois	68.26	63.67	115.67	96.95	56.56	46.37	90.39	43.60	72.58
Indiana	76.58	2.89	89.27	100.32	27.01	2.69	7.34	1.37	54.99
Iowa	54.71	11.59	12.58	78.64	37.75	63.80	49.18	18.87	58.41
Kansas	66.06	8.96	0.00	80.02	31.51	11.38	72.47	20.48	52.04
Kentucky	77.49	24.68	45.55	64.40	16.96	5.04	48.50	11.67	46.83
Louisiana	60.65	5.77	12.83	87.96	14.43	4.81	23.09	16.36	49.14
Maine	59.79	7.56	172.82	40.78	109.17	6.17	39.12	30.86	37.16
Maryland	102.05	12.21	59.39	61.80	43.19	6.30	104.61	66.46	59.87
Massachusetts	43.53	15.47	130.61	66.94	51.93	11.90	78.25	117.24	53.86
Michigan	95.80	19.61	45.12	106.83	74.30	12.63	61.62	0.00	67.26
Minnesota	69.52	0.00	152.42	77.74	38.11	130.99	17.15	0.00	71.96
Mississippi	65.19	3.72	65.18	43.05	30.28	0.58	20.18	8.33	33.08
Missouri	73.13	11.03	0.00	81.60	10.92	3.42	31.71	7.72	49.20
Montana	49.01	5.41	40.80	43.72	52.53	15.30	81.09	88.39	43.74
Nebraska	92.99	14.51	105.01	125.77	63.52	11.79	26.54	33.62	74.79
Nevada	65.40	11.08	31.67	63.34	39.59	37.61	31.67	0.00	47.62
New Hampshire	60.27	27.85	150.38	76.40	57.19	12.26	31.13	69.05	54.74
New Jersey	64.66	7.70	122.82	97.10	104.42	73.16	287.40	32.01	83.62
New Mexico	79.08	4.85	114.14	27.50	124.37	4.46	17.77	20.19	34.04
New York	62.71	16.84	91.37	77.86	70.48	32.07	80.87	0.00	54.50
North Carolina	135.82	24.89	0.00	73.49	98.34	7.56	16.87	18.91	63.59
North Dakota	35.28	1.37	0.00	73.46	34.28	34.77	31.43	63.82	49.27
Ohio	104.94	0.00	115.29	94.35	38.65	0.00	58.40	66.18	68.12
Oklahoma	63.48	4.43	73.38	46.28	18.70	1.07	39.76	63.43	40.40
Oregon	45.28	12.18	99.45	77.64	46.85	6.09	42.88	131.18	56.03
Pennsylvania	73.56	10.27	27.38	78.72	70.16	3.76	28.52	0.00	48.19
Rhode Island	54.35	375.01	0.00	91.84	125.45	13.39	40.18	169.65	86.52
South Carolina	131.15	23.07	31.51	75.46	83.40	55.60	34.75	27.80	74.62
South Dakota	60.56	16.07	107.15	76.53	80.36	10.71	48.22	160.72	63.91
Tennessee	79.70	6.99	19.98	57.09	27.47	3.25	161.84	26.97	50.65
Texas	120.08	18.31	60.69	122.45	93.98	17.21	195.26	121.50	98.38
Utah	63.41	16.60	121.35	90.90	49.67	20.72	6.60	297.45	83.06
Vermont	55.47	40.30	99.05	35.13	73.44	18.36	63.53	89.58	44.46
Virginia	69.57	17.04	0.00	42.42	0.00	6.20	93.37	20.88	39.80
Washington	65.16	7.94	62.47	7.40	27.86	23.05	35.71	29.56	28.14
West Virginia	74.02	9.05	9.05	51.71	8.37	0.51	13.48	1.02	36.70
Wisconsin	70.42	11.25	41.84	76.94	36.29	6.58	47.69	7.08	48.89
Wyoming	40.80	14.18	71.28	67.02	180.03	6.55	126.57	67.65	50.41
D.C.	96.57	34.41	154.84	97.80	68.71	22.98	63.48	7.78	68.73
Avg. percent served	80.45	21.38	71.61	76.66	54.76	19.27	86.65	44.65	59.23

Table 6.13

PERCENT OF HANDICAPPED SERVED, ASSUMING
DIFFERENT POPULATION BASES

Population Base ^a	Percent Served
General population	
Age cohort	
0-21 years	36
0-17 years	44
5-17 years	59
School population enrollment	65
ADM	68
ADA	71

^aSchool population statistics are from *Digest of Educational Statistics, 1971*, National Center for Educational Statistics, 1972, p. 28. ADA and ADM estimates for 1970-71 were not available. These figures were estimated by taking 1967-68 ADA and ADM figures and multiplying by the growth in enrollment from 1967-68 to 1970-71. General population data are from the 1970 Census of Population. The implicit assumption in this estimation method is that the incidence rates are the same for the school population as they are for the general population of school age.

ment, average daily membership (ADM), and average daily attendance. ADM is a measure of the number of students who are supposed to attend class. ADA is a measure of those who actually attend. The difference, of course, is due to absenteeism.

When the population base is the general population age cohort that is served by the public schools, 5-17 years, the percentage served is considerably higher than when all youth (0-21) are taken as the base.³³ From the preceding discussion we can conclude that the public schools are serving a majority, but not nearly all, of those handicapped children of traditional school age. But there is great variation across the states and across the types of handicaps, leaving much room for improvement in the amount and equity of special education services delivered. Many handicapped youth are not being served, however, because they are either too old or too young by traditional school age standards, or have dropped out or never been admitted to the public school.³⁴ If one assumes that the general population 0-21 age cohort is the proper population to use, then some 64 percent of the handicapped are not being served. This is approximately 5.3 million children. If one assumes the public schools should be serving just those enrolled (age 5-17), neglecting the private school population, then perhaps 1.7 million children are not being served. No matter what one

³³ An often quoted figure is that 60 percent of the handicapped are unserved by special education. This calculation uses the 0-20 age cohort as the base population. Incidence rates for ages 0-4 are assumed to be one-half of those for the 5-20 age cohort. See "Short Term Analysis Issue in the Education for the Handicapped," prepared by Bureau of Education for the Handicapped, and Exotech Systems, Inc., November 1971.

³⁴ We were unable to locate reliable data on the number served in private schools.

assumes, many youth are unserved, and if the policy were to increase the number served, then a two-pronged attack is needed. First, special education for those in school would have to be expanded. Second, younger and older youth population (generally not considered the province of the public school) would have to be included in the programs.

The above analysis also demonstrates that numbers can be selected to substantiate almost any position. In any event, policy should be based not only on the number served, but also on the type and quality of service being received. The variation in the amount of resources input to the program is discussed later in this section. Though this would be a logical place to discuss variation in program output, such a discussion is not within the scope of this report. Even if it were, it would not be too enlightening because of the dearth of information on the effectiveness of special education programs.

Though it is difficult to get an estimate of the percentage served because of the various assumptions underlying each estimate, we can say something about the percentage served for each handicapped group, holding the assumptions constant. Table 6.12 reveals that a relatively large percentage of the mentally retarded are being served compared to the emotionally disturbed and the learning disabled, even using the low estimate incidence rates for the latter two disabilities. The hard of hearing and the emotionally disturbed are the most underserved categories. Table 6.12 also shows the variation in the percentage served among states. The minimum percentage served in the mentally retarded category is 35 percent in North Dakota, but only 13 states fall below 60 percent served. The chances that a mentally retarded child will be served are fairly good no matter what state he lives in. The same cannot be said for the emotionally disturbed. Because of the variation in the percentage receiving service for the emotionally disturbed, the probability that an emotionally disturbed child will be served varies greatly from state to state, and the variation among school districts may be even greater than among states. A look at intrastate programs, however, is outside the scope of this research.

The last column in Table 6.12 shows that there is a large variation in the percentage served among states. An initial attempt was made to analyze this variation by using a simple linear regression model. It was hypothesized that the percentage served was a function of whether special education was mandated, the population density of the state, and the per capita income in the state. The estimated model was

$$P = 52.5 + 8.9M + .024D - .001I \quad R^2 = .20,$$

(1.8) (2.1) (.3)

where P = percent served,

M = 1 if special education is mandated, 0 otherwise,

D = population per square mile,

I = per capita income.

The model shows that the only significant variables (10 percent level) were the population density and the mandated variables. That is, the percentage served seemed to be the same regardless of per capita income after the data were adjusted for population density and program mandate. One hypothesis that is in accord with population density being significant is that a lack of a sufficient number of hand-

icapped youth in low-density areas makes special education an impractical alternative because of the high cost of serving a small number of children. This hypothesis is explored further in the next subsection on determinants of state and local spending. The low value of the coefficient of determination implies that other forces determining the number served have not been incorporated into the model. More research is needed to isolate the determinants of the percentage served in order to help design an effective policy for increasing that percentage.

State and Local Expenditures Per Handicapped Student

The percentage served in any handicapped category is not an adequate indicator of the quality of the program that is being offered. Rossmiller found that the costs for special education vary quite widely. In the sample districts used in that survey, the cost per pupil for a program for the educable mentally retarded varied from \$826 to \$2358.³⁵ The same wide variation was found among the states. Table 6.14 presents the average state and local special education expenditure per handicapped child served, by type of disability. The United States average is \$776 per handicapped student. The reported average annual special education expenditure for a speech-impaired student is \$170; for a deaf child it is \$3067. The reported variation across the states for all handicapped children is extreme: from \$213 in the lowest state to \$1705 in the highest (excluding Alaska). The reported variation across states within a single handicap is even more striking. For example, the range for deafness is from less than \$100 per pupil to nearly \$10,000 per pupil annually; however, these figures understate the amount of funds going to the handicapped. They also receive services from the regular education program, and in some states these services may not have been reported in estimating the funds for educating the handicapped. The estimates presented here are the funds reported by the states for special education only. We do not believe these reported data represent the total cost of educating children who presently receive some special education services. As an example of data inconsistencies, the reported expenditures for special education averaged \$776, which is less than the average expenditures of \$858 for the education of nonhandicapped youth.³⁶ Other sources use much higher estimates of the total average per-pupil expense for educating handicapped children; e.g., the U.S. Senate Labor and Public Welfare Committee uses \$1470.³⁷ Inspection of the budgetary data from the states broken down by type of handicap indicates that the expenditures are typically "line item" budget expenses identifiable as special education. Thus, for a speech-impaired student the reported \$170 is probably the excess cost of speech therapy above the cost of his education in a regular classroom. For a deaf child, on the other hand, the \$3067 reported expense is probably total rather than excess cost, since the deaf child would most typically be served in a special education classroom rather than in a regular classroom. If the speech-impaired are removed from the calculation of average per-pupil expenditures, the average figure jumps from \$776 to \$1271. Because of the lack of reliable special education cost data, total and excess costs are difficult to estimate. For instance, the total cost figure of \$1470 used by the Senate Committee

³⁵ Rossmiller, Hale, and Frohreich, p. 65.

³⁶ *U.S. Statistical Abstract*, U.S. Government Printing Office, Washington, D.C., 1971.

³⁷ As reported in "Handicapped School Children, Caught in School Aid Debate," *National Journal*, Vol. 5, No. 6, February 10, 1973.

Table 6.14
ESTIMATED AVERAGE EXPENDITURE PER HANDICAPPED STUDENT SERVED, 1972-73
(Dollars)

State	Mentally Retarded		Hard of Hearing	Deaf	Speech Impaired	Visually Impaired	Emotionally Disturbed	Crippled	Learning Disabled	Other Health Impaired	Average All Handicaps
	Trainable	Educable									
Alabama	435	543	865	748	98	378	737	712	813	791	425
Alaska	1,964	2493	2381	2100	2714	2400	2422	2125	2645	2,540	2463
Arizona	1,140	1285	2000	0	100	2705	1284	1282	1285	1,698	820
Arkansas	606	218	0	3813	9	4121	213	788	168	87	325
California	2,506	1336	4900	3500	117	2800	0	1412	1313	0	951
Colorado	0	643	0	0	88	1464	301	2220	0	2,006	476
Connecticut	1,874	1600	1793	0	252	2494	749	1343	924	0	910
Delaware	2,683	901	1625	3065	135	0	1349	2700	1687	2,747	950
Florida	1,452	1066	189	1771	150	1067	1205	633	695	0	712
Georgia	603	360	769	2770	395	3559	1369	0	1111	786	555
Hawaii	1,853	1171	625	3449	16	1882	2554	2471	912	2,240	795
Idaho	374	907	189	46	108	88	0	344	214	0	373
Illinois	1,251	1250	150	4778	188	1503	882	1668	1251	1,001	844
Indiana	1,046	548	715	1545	78	3642	1319	1784	1405	1,113	377
Iowa	1,207	929	2512	5143	209	1357	304	767	943	802	568
Kansas	1,255	885	1559	0	120	1028	896	1405	631	425	535
Kentucky	896	595	595	896	234	1028	1046	895	1272	0	481
Louisiana	650	370	333	400	47	467	600	700	500	400	213
Maine	842	255	265	2396	80	714	541	620	418	1,059	386
Maryland	1,000	200	1000	1000	50	1000	1000	1000	1000	1,000	397
Massachusetts	1,737	1585	431	3099	106	2660	3708	634	410	0	734
Michigan	2,378	1086	2108	8357	189	2364	1601	1156	0	0	937
Minnesota	1,496	1213	0	2464	149	2688	720	3014	0	325	817
Mississippi	624	581	1025	2600	53	1661	378	522	706	33	383
Missouri	0	1000	1000	0	1000	1000	1000	1000	1000	1,000	1004
Montana	980	688	2736	5000	508	2427	167	213	0	10,000	549
Nebraska	1,102	1010	957	3534	700	2492	982	1392	119	0	922
Nevada	1,250	1061	1786	2067	179	1000	1118	1250	0	0	708
New Hampshire	2,081	1363	449	4596	109	1954	2551	1500	1560	1,279	919
New Jersey	917	610	1216	1168	138	1165	345	642	921	249	561
New Mexico	1,000	900	893	498	500	499	1000	896	899	900	815
New York	3,250	2800	1200	5250	125	4200	3500	3700	0	2,700	1705
North Carolina	765	449	1683	0	88	1858	696	1307	305	972	373
North Dakota	1,244	931	1583	0	163	667	127	5591	119	306	366
Ohio	2,005	1826	0	2874	174	2204	0	3030	1309	1,186	910
Oklahoma	567	469	925	80	81	1624	1039	709	441	124	319
Oregon	1,913	1028	1354	1035	125	7676	1086	878	171	880	410
Pennsylvania	2,128	1176	891	2530	168	1414	2530	2875	0	2,875	718
Rhode Island	4,333	720	333	0	100	1068	2200	1000	1000	333	563
South Carolina	649	427	273	588	63	330	125	234	341	0	256
South Dakota	417	750	667	3333	40	2667	500	3000	83	500	368
Tennessee	950	750	1000	1000	95	1000	1500	900	1000	750	563
Texas	621	726	751	1676	70	1125	737	724	696	676	435
Utah	1,299	1088	483	827	169	626	1290	1612	514	0	555
Vermont	1,358	884	873	2908	133	1221	505	4847	285	327	614
Virginia	1,718	1718	1718	0	133	0	1718	775	400	260	1005
Washington	1,101	654	1266	1478	1144	1037	662	1083	381	974	1218
West Virginia	648	478	560	633	76	703	533	1020	578	848	299
Wisconsin	1,925	182	2382	9862	199	7511	2891	4664	2591	268	1101
Wyoming	1,600	1449	477	3796	173	442	1600	136	877	67	706
D.C.	2,161	731	2919	2916	196	2903	2638	3552	2109	3,551	1057
U.S. average	1,757	1045	936	3067	170	2186	1214	1530	1015	822	776

cited earlier uses the assumption that the excess cost of educating the handicapped child is one-half of the total cost. The factor of one-half and the total cost figure of \$1470 are reasonable estimates, if one considers that the cost of education is highly dependent on the teacher/student ratio, and that it is not unrealistic to have one-half as many handicapped students as regular students per teacher, on the average.

What the cost of special education should be is inextricably tied to the type and structure of the program (special classrooms, itinerant special teachers, etc.), proportions of handicapped youth being served, and the effectiveness of the program. Since very little is known of the relation between resources expended and the effectiveness of special education, one is forced to talk in terms of the cost if special education is delivered in a specified way. In a subsequent report, we will attempt to describe the cost of service to aurally or visually impaired youth as a function of factors such as the type and number of handicapped youth to be served; the type and size of teaching personnel and classrooms to be used; and the cost rates for teachers' salaries, buildings, equipment, and so forth. Such a cost model approach aids in understanding what proposed increases in Federal funds for special education will buy in terms of services delivered to children.

Part of the reported variation in expenditures across states is due to definitional problems in the types of handicapping conditions. Some states grouped their deaf and hard of hearing into one category, for example, while others did not. Such groupings will distort the amount spent on each disability. Some portion may also be attributed to different assumptions made about what costs to include in the cost-estimating procedures used by the states. One state, for example, estimated that service costs were \$1000 per student for most major types of disability. Still, most variation is probably due to the different resource levels provided in each state. Again, however, we are in a position of saying that some states pay more for special education, but we have virtually no information on whether these states are achieving more.

Another measure of state and local effort is the amount spent on education of the handicapped in comparison to the total number of children (handicapped and nonhandicapped) in the public school system. While a state may be spending a large amount per child served, it may not be serving a large percentage of the handicapped. By looking at the amount spent, normalized for total public school population size, we get a better idea of fiscal effort being put forth in each disability category.

Table 6.15 shows the average amount reported spent by each state on each handicap for each youth (handicapped and nonhandicapped) in the public school system. Only \$44 per total average daily attendance is spent on the handicapped, while the average expense for elementary and secondary education is \$858.

Table 6.15 also shows the coefficient of variation (CV) among the average reported expenditures for each disability. The CV is a measure of the dispersion of the distribution.³⁸ The larger the coefficient of variation, the greater the variation in

³⁸ The CV is defined as

$$CV = \left(\frac{\sum_{i=1}^n (X_i - \bar{X})^2}{n - 1} \right)^{1/2} / \frac{\sum_{i=1}^n X_i}{n}$$

Table 6.15
DISPERSION MEASURE OF STATE AND LOCAL EXPENDITURES FOR
SPECIAL EDUCATION

Type of Handicap	Average Expenditure Per ADA	Standard Deviation	Coefficient of Variation
Mentally retarded, trainable	\$ 4.61	\$ 3.30	71.645
Mentally retarded, educable	14.61	7.78	53.236
Hard of hearing	1.19	1.55	131.030
Deaf	1.69	1.75	103.714
Speech impaired	5.98	7.97	133.367
Visually impaired	1.20	1.07	88.599
Emotionally disturbed	4.51	5.97	132.356
Crippled	2.30	3.38	146.610
Learning disabled	4.87	6.20	127.303
Other health impaired	1.58	2.35	148.822
Total	\$43.83	\$24.43	55.744

expenditures per ADA among the states. The data show that expenditures on the mentally retarded do not vary as much across the states as those for the other disabilities. This can reflect either a larger variation in the percentage served or a larger variation in the expenditures per child served for the other types of handicaps.

Determinants of State and Local Spending

If one objective of Federal policy is to stimulate state and local spending on special education, it is important to understand the determinants of that spending. Just why state and local districts spend at various levels is a complicated issue. Some simple models of state and local behavior can help clarify the issue.

Per-pupil spending on special education should reasonably be a function of income per capita. The higher the income, the more one would expect to be spent on the education of the handicapped. This is true of regular education,³⁹ and it is reasonable to believe that it would be the same for special education.

Spending on special education should also be a function of whether such education is mandated. Even without legislation, many local districts would provide such services. Legislation, however, would have an effect on some districts that would not otherwise provide it. Therefore, it is hypothesized that state and local education expenditures would be affected positively by legislation mandating the provision of special education services.

The amount spent on special education may also be a function of population density, although whether high population density should increase or decrease emphasis on special education is not clear. Low population density areas might have fewer handicapped youth per school district because travel times would limit the geographic size and, hence, the population size a school district serves. Since it is

³⁹ S. M. Barro, *The Impacts of Grants in Aid to State and Local Education Expenditures*, The Rand Corporation, P-4385, 1970, p. 21.

reasonable to expect that economies of scale will make special education relatively less expensive when larger numbers of pupils are involved, the expenditure rate may be inversely related to population density. The low density district may simply not offer special education, since the small size program and high cost could outweigh benefits. However, if the high density district were to offer the program, their spending per capita on special education would obviously exceed that of the low density district. This would imply that special education expenditures were positively related to density. Therefore, population density exerts two conflicting forces on special education expenditures.

Another possible determinant is the method of financing special education within each state. Whether the state reimburses all excess costs, matches local spending, or provides flat grants will make a difference in the behavior of the local district. Unfortunately, it was not possible to get adequate data on this variable to include in this description. It should be gathered, however, for extensions of this research.

The model that has been discussed is assumed to be linear:

$$S = a + bI + cM + dD,$$

where S = special education expenditures per ADA,

I = per capita income,

M = 1 if mandated, 0 if not mandated,⁴⁰

D = population per square mile.

Using 1971 data,⁴¹ the following coefficients of the model were estimated:⁴²

$$S = 36.3 + .020I - .003D + 6.56M \quad R^2 = .53$$

(5.2) (.3) (1.6)

Income has by far the most significant coefficient and is related to large changes in the special education expenditure variable. The model estimates that for every dollar increase in per capita income, two cents goes to special education per ADA. This could mean that Connecticut would spend some \$46 more than Mississippi because of the income effect. Since the mean value of S is \$36, it shows the dramatic relation to special education that incomes may have.

The variable, density, is not statistically significant. It could be that the two conflicting forces potentially caused by density just cancel one another out. Using state data, however, is probably too high a level of aggregation to see behavior in individual school districts. The impact of density should be studied more closely with data from school districts.

Mandating legislation was hypothesized to have a positive impact on spending

⁴⁰ States that only provided permission for the local districts to have special education or required a minimum of children (greater than one) for special education were considered not to have mandated special education. Information on existing legislation was taken from The Council for Exceptional Children, *Digest of State and Federal Laws: Education of Handicapped Children*, Arlington, Va., 1971.

⁴¹ Data on average daily attendance were taken from the *Digest of Educational Statistics*, p. 26. Income data were taken from the *U.S. Statistical Abstract*, p. 121. The income data were for 1969, but because income is a slow-moving function, the year lag should not distort the analysis. Data on population density were also obtained from *U.S. Statistical Abstract*, p. 13.

⁴² T-ratios are shown in parentheses below each equation.

and, in fact, had a positive statistical relation. The coefficient, however, is only significant at approximately the 15-percent level of confidence.

The preference of states for dividing funds between special and regular education was also subject to investigation. A model similar to the one above was hypothesized where the ratio of special education expenditures to total current expenditures on the total school program was regressed against the variable measuring density, mandated legislation, and per capita income. The estimated model is shown below:

$$S/E = -1.01 + 1.10 M + -.0005 D + .0017 I$$

(1.68) (-.32) (2.75) $R^2 = .30,$

where S/E = Special Education Expenditures/Current Expenditures for Public Elementary and Secondary Schools.

Once again, the density variable is not significant in explaining differences in emphasis on special education among the states. Whether the state has mandated legislation, however, is related (10-percent confidence level) to spending preferences.

Again, income is highly correlated with the amount of funds going to special education. The coefficient of the income variable is significant at the 1-percent level of confidence. This means that not only do high income states pay more for special education, but they also give it more emphasis relative to regular education.

We noted previously that percentage of handicapped served was related to the density of the state. Here, however, we have seen that both special education expenditures per ADA and special education expenditures as a percentage of total expenditures are not related to density. This implies that, while the less densely populated states are serving fewer students, they are spending more on each of those served. To verify this, we used the same type of model and showed that expenditures per pupil served are negatively related to density.

The utility of such models is restricted by inconsistencies in the cost data cited earlier. But these exploratory models do indicate some of the major factors relating to special education expenditures. Further analyses with other potentially explanatory variables are needed before we can draw firm policy conclusions.

STATE AND FEDERAL EXPENDITURES FOR THE EDUCATION OF THE HANDICAPPED

Previous subsections have examined Federal and state and local spending separately. The programs supported by these funds are for the most part not distinct, and Federal funds are intermingled with state and local funds in their operation. To obtain an idea of the scope and composition of the funds going to the handicapped, it is necessary to look at the total contribution each level of government makes.

State and local expenditures by disability were presented in Table 6.9. Most of the Federal funds are not allocated by disability. Table 6.16 presents the state and local expenditures and an estimate of the Federal allocation of funds among handicapping conditions. This estimate was made by assuming that Federal funds that

Table 6.16

TOTAL SPECIAL EDUCATION EXPENDITURES BY TYPE OF HANDICAP

Type of Handicap	State and Local (\$ million)	Federal (\$ million)	Total (\$ million)	Per Child Served (\$)
Mentally retarded, trainable	260.0	45.5	305.5	2064
Mentally retarded, educable	840.0	75.9	915.9	1217
Hard of hearing	55.0	13.6	68.6	1247
Deaf	91.0	42.5	133.5	4767
Speech impaired	251.0	21.8	272.8	197
Visually impaired	66.0	19.2	85.2	3043
Emotionally disturbed	258.0	35.0	293.0	1472
Crippled	210.0	10.0	220.0	1718
Learning disabled	250.0	32.1	282.1	1227
Other health impaired	84.0	19.2	103.2	1086
Total	2364.0	314.9	2678.9	879

could not be classified directly⁴³ were distributed in the same proportion as EHA-B funds. The distribution of EHA-B funds closely resembles the distribution of state and local funds among handicapped groups. Since the state and local expenditures play a dominant role in shaping the program, it is not unreasonable that the remaining Federal funds (teacher training, research, Title III, etc.) will be used ultimately in proportion to the size of the state and local program.

Total expenditures on education of handicapped youth were approximately \$2.7 billion. Recall that this is an estimate of the amount budgeted for special education of handicapped students. Some handicapped students also receive services as part of the regular school program.

Table 6.16 also indicates the average cost per handicapped child served, by disability. Education for the aurally or visually impaired is by far the most expensive.

One Federal Government goal is to serve 100 percent of the handicapped population.⁴⁴ Table 6.17 shows an estimate of the increase in the annual special education expenditures necessary to achieve this objective. In this estimate the Federal roles in training and research would be expanded in proportion to the change in the population served. A further assumption was that the average cost of serving children is equal to the marginal cost of expanding service. The number presently unserved in the age 5 to 17 general population was derived previously.

As shown in Table 6.17, an estimated \$2.5 billion per year would have to be added to the special education expenditures to provide elementary and secondary education to 100 percent of the handicapped youth aged 5 to 17 at present service quality levels. Over 48 percent of this increase would go toward educating the emotionally disturbed, who presently consume only 10 percent of the expenditures. An attempt to serve all handicapped children would require a large change in the percentage of funds going to each disability group. A possible implication of this

⁴³ Federal programs classified directly were Federal Schools for the Deaf, American Printing House for the Blind, EHA-B, P.L. 89-313, Deaf-Blind Centers, and EHA-G.

⁴⁴ Statement by Duane J. Mattheis, U.S. Deputy Commissioner of Education for School Systems, *Hearings*, p. 359.

Table 6.17

**INCREASE IN SPECIAL EDUCATION EXPENDITURES NEEDED TO
SERVE ALL HANDICAPPED YOUTH**

Type of Handicap	Incremental Number	Incremental Expenditures (\$ million)
Mentally retarded	289,000	393
Hard of hearing	204,000	254
Deaf	11,000	52
Speech impaired	423,000	83
Visually impaired	24,000	73
Emotionally disturbed	835,000	1229
Crippled	(a)	(a)
Learning disabled	287,000	352
Other health impaired	36,000	52
Total	2,109,000	2488

^a Crippled are included with "other health impaired."

need for a large change from current practice is that the 100 percent service level cannot be reached by just adding money to the total program. Such additions are likely to be allocated among handicaps in much the same way as the current budget because of institutional forces that tend to make budget proportions rigid. To increase funds for a particular disability would require categorical funding or tight regulations—a type of funding and control that presently does not characterize the Federal program.

Four important qualifications must be put on the implications of this information. First, estimates of incidence levels of disabilities and marginal costs are based on data of questionable quality. Second, the appropriate measure of the population size against which to apply the incidence levels is a matter of judgment. Third, some of those handicapped not served by special education are presently in school, and the increase in special education expenditures if they were to be served is partially offset by a reduction in the regular educational services that would no longer be delivered. A more important qualification is that this information does not imply any normative judgment about what the proper allocation of resources among the disabilities should be, or the proper amount of resources needed per child to obtain a quality education.

The cost estimates presented in Table 6.17 attempt to answer the question, "What increase in special education expenditures would be necessary to enroll 100 percent of the handicapped children in programs of today's present quality?" Equity considerations would argue that 100 percent coverage is a proper objective, but it should not be a solitary one. Another consideration is the effectiveness of programs in altering behavior or teaching cognitive skills. If programs for the emotionally disturbed, for example, are not effective in restoring mental health, it would not be good policy to expand them just to increase the equity coverage. Estimates of the marginal benefits of increased expenditures, however, are well outside the scope of this report.

SURVEY RESPONSES FROM STATE EDUCATION AGENCIES

The Rand survey described in Appendix B included administrators of special education in each state. Primarily because of the excellent help received from HEW's Bureau of Education for the Handicapped, including a personal letter to each survey recipient requesting his cooperation, the response rate was 70 percent. Most of the information was program descriptive and is presented elsewhere in this section or will be used in a subsequent report to support recommendations for program improvement. In general, the cooperation we received from the states on this survey was excellent; however, response quality was limited somewhat by the information available at the state level.

To improve special education programs, it is necessary to understand the problems or obstacles facing those who provide the service. Part of the questionnaire asked administrators to delineate problems they were encountering, but although 70 percent of the states' education agencies responded to the survey, only 14 percent responded to this particular question. Those responses, however, generally agreed with the problem descriptions that we heard in our site visits to five states. Therefore, the problems enumerated below are probably much more widespread than the response rate would indicate.

Growing Resistance to Providing Funds for Education of the Handicapped. Funds for special education have grown to a level where they are no longer an insignificant part of the budget. Under the fixed budget constraint that is occurring in more and more states as well as in the Federal Government, increased funds for special education imply a reduced budget for some other programs. Given the politics of the budgetary process, such a growth in expenditures for special education must inevitably lead to resistance.

Inadequate and Uncertain Funding. A constant complaint was that there are inadequate funds for special education. In the eyes of program administrators, however, this problem is common to almost all programs. Many feel that the uncertainty of Federal spending levels makes planning very difficult. The timing of the Federal Budget cycle and the school calendar also means that projects have to be designed, approved, and implemented in too short a period for adequate administration of these processes.

Shortage of Personnel. Although some states have legislated that all handicapped children be served, state administrators have recognized that there are not enough adequately trained personnel to handle such a task. One state recommended placing more emphasis on the teaching of exceptional children in the curriculum for regular teachers. This would not only aid the instructional process by perhaps letting the handicapped child remain in the normal classroom, but would also increase the teacher's opportunities to correctly identify those in need of special education services.

Problem in Servicing Low Incidence Populations. One state mentioned difficulties in servicing low-incidence populations such as the deaf-blind. This problem will vary in magnitude depending on population density. For example, in many small school districts there may not be enough partially sighted children to provide an adequate program at a reasonable cost. In major metropolitan centers, however, finding the critical mass of students to achieve necessary economies of scale would be no problem.

Lack of Program Coordination. Five of the major programs are usually handled by three different departments at the state level. Titles I and III, EHA-B and P.L. 89-313, and Vocational Education are administered separately. Although the three groups are supposed to be coordinated, we noticed that this coordination varied from excellent to practically nonexistent. Several administrators stated that they never had any impact on the decisions of the others—although they signed the project coordination sheet when Federal regulations required it.

Lack of State Support for Special Education. Several administrators thought that the local response was heavily influenced by the size of state aid for special education. One state, for example, was paying only 25 percent of the excess cost. This was felt to be an insufficient incentive for many of the poor districts to provide special education.

No Pre- and Post-School Program. One state felt that the education system should incorporate both pre- and post-school programs for handicapped children. While some states now allow preschool programs for handicapped children, it has not been a widely adopted concept. For some handicapping conditions, age six is past the optimal time to start the child's educational program. Similarly, it was suggested that schools provide occupational training and guidance for those over 18.

PREVIOUS RESEARCH AND DATA AVAILABILITY

During this study, several policy questions reappeared in our discussions with persons involved in planning for the education of the handicapped.

- What is to be gained from investing in the education of the handicapped?
- How should benefits be measured?
- How can state and local governments be stimulated to increase the educational services for the handicapped?
- What programs are effective for what types of handicapped?

This section reviews a sampling of existing research and data relating to these questions.

Research

A dearth of research is available on the cost-effectiveness of programs for educating the handicapped. This is not true of other types of education. The value of general education is the central issue of a rich and growing literature.⁴⁵ Vocational

⁴⁵ See H. A. Averch et al., *How Effective is Schooling, A Critical Review and Synthesis of Research Findings*, The Rand Corporation, R-956-PCSF/RC, March 1972.

and technical education has been the subject of extensive study.⁴⁶ Why, then, has education for the handicapped been neglected?

Our view is that the neglect stems from the difficulty and cost of such studies, coupled with the lack of available data. No adequate measure of output is regularly collected on special education programs. The analyst cannot rely on various types of achievement tests, for example, to be part of the public education record on handicapped children. Also, he must distinguish between differences in program output due to the program itself and the output or effects due to the differences in innate abilities of the children served.

In compensatory education studies, the standard procedure is to design control groups or adjust output results for innate abilities by using standard measures of IQ. In dealing with the handicapped, however, the analyst should adjust for the severity of the handicap as it affects the learning process. But how can he adjust for differences in visual acuity among different groups of youngsters in different programs? The Snellen acuity rating scale is not really an indicator of the severity of the handicap if the student is being taught mathematics, for example.

These limitations imply that the researcher must develop measurement instruments and control groups and collect a great deal of new data. For any large sample, the costs of such research would be very high. Even then, such a study would have to beware of a defect occurring in many of the compensatory education studies, i.e., looking only at short-term output measures such as reading scores. The value of short-term measures has been questioned when applied to the regular school population. Those short-term measures are perhaps more questionable in special education where one possible primary goal is the long-term adjustment to living in normal society. Because of the lack of output or effectiveness information, most studies have tended to focus on the input side of special education.

The most comprehensive treatment of the level of special education is a study by R. A. Rossmiller, James Hale, and Lloyd Frohreich,⁴⁷ which had five objectives:

1. To catalog procedures for identifying exceptional children and review existing literature on incidence levels of each category of exceptionality.
2. To estimate the number of exceptional children based on population and incidence level estimated.
3. To examine the nature of exceptional children programs which are reputed to be of high quality.
4. To estimate the cost differentials which are associated with educational programs for the various categories of exceptional children relative to the cost of regular school programs provided for normal children.
5. To estimate the cost of educational programs for exceptional children provided in private schools and in public facilities not associated with the regular public school system.

The first two objectives are met by reviewing literature on incidence rates and population projections. The study does not contain much data on the identification processes that are being used, however. Its main contribution is its analysis of costs

⁴⁶ E. M. Stromdorfer, *Review and Synthesis of Cost-Effectiveness Studies of Vocational and Technical Education*, Ohio State University, Columbus, August 1972.

⁴⁷ Rossmiller, Hale, and Frohreich.

in a selected sample of school districts and residential schools, which reveals a wide variation in special education expenditures. Cost for an educable mentally retarded, for example, ranged from \$708 to \$2358 per pupil. The study shows that there is not just one program for the educable mentally retarded, but a vast number from which the school administrator must choose. While the volume gives the decisionmaker some idea of the program's price, he has almost no information about the program's output. The question of whether high expenditures do make a difference in outcome never gets answered. This is not meant to be a criticism of the Rossmiller study, since this question was not a focus of the research. It is really a call for more research into the relationship between inputs and output so that more rational resource allocations can be made to special education.

Exotech Corporation is now conducting another examination of programs for educating the handicapped.⁴⁸ Part of the study involves a detailed survey of 675 public school districts. The survey asks for information on

1. Characteristics of the school district (size, location, etc.).
2. Size of handicap population served by disability.
3. Receipt of Federal revenues.
4. Description of the special education program.
5. Types of evaluation being performed in special education.
6. Effectiveness of EHA-B projects.

When the survey is completed, this study should give the best description of special education that exists. If the sample is representative, the study should provide better estimates than we have now of who is being served and who is not. It should also provide an estimate of the nature and extent of effectiveness analysis being performed at the local level.

Another type of study describes problems encountered in special education, and then draws on "expert opinion" for solutions. An example is a study by H. D. Babbidge, Jr. et al., *Education of the Deaf, a Report to the Secretary of Health, Education, and Welfare by his Advisory Committee on the Education of the Deaf*, U.S. Department of Health, Education and Welfare. This 8-year-old study presents an excellent summary of the problems encountered in educating the deaf. It also is prototypical of the best of other committee reports on selected disabilities in that it contains a great deal of existing research and expert opinion in one volume. The report's listing of the major areas where improvement is needed is similar to those of today, calling for early identification and treatment of the deaf as well as for more research into finding better methods for teaching the deaf. There is no analytical treatment of what the costs and benefits of early identification and treatment would be, however. Since education was felt to be the primary responsibility of the states, the report does not recommend a large Federal role in the education of the deaf. It suggests the Federal role should be the following:

1. To provide incentives for the state to plan special education services more effectively.
2. To sponsor post-secondary demonstration programs that attempt to integrate

⁴⁸ This study is being sponsored by the office of Planning, Budgeting, and Evaluation of the U.S. Office of Education and has not been published as of this date.

the deaf into the normal college curriculum.

3. To develop a residential technical school for the deaf.
4. To establish a National Advisory Committee on the Education of the Deaf in order to better coordinate the programs of the Federal Government.
5. To increase emphasis on research for educating the deaf.

Many states also conduct their own investigations of what services are being provided to handicapped children. Perhaps the most extensive is the recently completed Fleischman Report for New York State.⁴⁹ The mandate of this study was to study all facets of public education in the State of New York and not just special education. One chapter of the report discusses the number of children receiving services, problems in diagnosing handicapped children, isolating handicapped children in special schools and classes, financing the education of handicapped children, and training teachers for the handicapped. The report recommends a regionalization of special education, increased effort in identifying handicapping conditions, and increased incentives for the local district to provide special education services. The recommendations stem mainly from expert opinion. There is no data-based argument, for example, of what the impact on local efforts would be under different state-aid formulas for special education. In a field where data are so sparse, however, the report could hardly have been done otherwise. A review of the data deficiencies, to which we now turn, will make evident the constraint on planning imposed by the lack of data.

Data

One of our survey findings was that if the Federal Government did not require certain information for reporting purposes, it was highly likely that these data would not be available in state agencies. Therefore, much of what the states can provide is already in Federal reports.

The *Description of Projected Activities for the Education of Handicapped Children* report submitted by each state to the U.S. Bureau of Education for the Handicapped contains the most complete information available on the expenditures and population served. The reliability of these data, however, is questionable, and the FY 1974 report form requires considerably less data. School districts do not generally account for special education expenditures separately. State administrators who fill out these particular reports, then, must estimate the size of the local contribution to special education. The methodology behind such estimates is not reported. One state administrator said the estimate was based on what he thought the total cost of the program would be minus the state contribution. While this is a reasonable approach, it leads to less than precise estimates of expenditures. There is uncertainty about the number served also. Some states do not finance special education on the number of children but rather on the number of classes offered. The number of children in a class can vary quite widely (e.g., 5 to 16 in one state). One administrator used the maximum class size to estimate the number being served. This would, of course, lead to an overestimate. Some states, it appeared, exclude their residential schools in estimating state and local expenditures. This is more likely to happen

⁴⁹ M. Fleischmann, *Report of the New York State Commission on the Quality, Cost and Financing of Elementary and Secondary Education*, Albany, 1972.

when the residential schools are not run by the Department of Education but by a separate state organization.

Individual projects under EHA-B and P.L. 89-313⁵⁰ are summarized to yield some very detailed information. Project expenditures by resource category (administration, instruction, etc.) are available on both programs. The number of children served and the expenditures by type of handicap are also provided.

Title III reporting forms also require information on the resources flowing to the handicapped. The form asks for information on expenditures and the number served by handicap. The quality of the reporting under Title III can only be described as abysmal. In many instances, the state reports available to the U.S. Office of Education were not complete or there were such obvious discrepancies in the figures reported in different places in the same report that they make the reports of very questionable value as valid indicators of how Title III funds are being spent on the handicapped.

State reports to the Federal Government on the Vocational Education Program present the numbers of handicapped participating and expenditures on the handicapped. These figures are not broken down by handicaps, however. Enrollment estimates are broken down by the type of vocational education (health, agriculture, etc.).⁵¹ Again, however, it is difficult to see how these figures can do more than give some idea of the size of the Federal commitment to vocational education of the handicapped. If the planner had to decide what types of vocational education to supply to which types of handicapped children, the data in their present form would not be of much use.

As indicated throughout this section, cost data are not entirely reliable. An effort should be made to standardize the assumptions that are made in reporting costs, and to enforce the requirements that cost be reported. Even if the costs reported currently were accurate, however, they would represent average costs and not necessarily the incremental costs needed for planning. In the current debate over proposed Federal legislation, a recurring question is "What is the excess cost of educating a handicapped child?" These data are generally not available from school districts because they account for cost by resource category (teacher, materials, etc.) rather than by program (reading, handicapped children, etc.). One method to overcome this dilemma is the development of generalized cost models⁵² that assist in the design and costing of special education programs. Such models could be used to simulate existing programs such as those reported in the Rossmiller study.⁵³ Exercise of the model could then reveal what part of the cost difference among programs is due to differences in resource consumption levels and what is due to differences in price levels. Also, a panel of experts could design a "good" special education program in terms of the level and composition of resources employed for each type of disability, and the model would be able to estimate the excess cost under the assumptions made by experts. This seems like a more reasonable approach to the problem of estimating excess cost than adopting the alternative of using median or average costs.

⁵⁰ U.S. Bureau of Education for the Handicapped, *Aid to the States Branch Information System, FY 1970—National Report*, Washington, D.C., 1971.

⁵¹ Bureau of Adult Vocational and Technical Education, Department of Health, Education and Welfare, *Vocational and Technical Education, Selected Statistical Tables, FY 1971*, Washington, D.C., 1972.

⁵² See L. A. Dougharty et al., *A Program Budgeting Cost Model for School District Planning*, The Rand Corporation, P-4953, January 1973, for an example of the design and use of such models.

⁵³ Rossmiller, Hale, and Frohreich.

7. FINANCIAL ASSISTANCE TO HANDICAPPED YOUTH

This section first summarizes Federal and state income assistance programs to handicapped youth. Next, a more detailed description of the Federal role and program objectives is presented, followed by information on handicapped youth served by the various financial assistance programs. Then, nonfinancial services provided by public welfare agencies and a survey of those agencies are described. And finally, previous research and data availability are discussed.

OVERVIEW AND SUMMARY

In 1970, financial assistance programs in the United States reached an estimated one million needy physically or mentally handicapped persons under age 22. Total annual expenditures on those programs were conservatively estimated to be \$634,544,000, of which the Federal, state, and local shares were 54.6, 34.6, and 10.8 percent, respectively. Tables 7.1 and 7.2 show a breakdown of assistance and youth served for the various programs: Social Security Disability Insurance (SSDI), Aid to the Blind (AB), Aid to the Permanently and Totally Disabled (APTD), Aid to Families with Dependent Children (AFDC), General Assistance (GA), and Income Tax Exemptions for the Blind (ITEB). Most of the financial assistance to handicapped youth is dispensed through the AFDC program, which is aimed at the needy rather than the handicapped. Table 7.3 data indicate the expenditures by types of handicapped youth.

Federal involvement in financial assistance began with the Social Security Act of 1935 and has grown to the point where most funds expended on needy handicapped youth are Federal, and two of the four major programs are federally operated. This dominant Federal role apparently evolved for two main reasons: (1) state, local, and private sources have had insufficient financial resources to provide socially desirable minimum income levels to an acceptable fraction of the needy population; and (2) under state and locally operated programs, a socially undesirable inequity in the distribution of funds across states has existed. While authorities disagree on what level of financial aid is adequate, and what distribution of funds is equitable, the President's Commission on Income Maintenance Programs¹ con-

¹ *The President's Commission on Income Maintenance Programs, Background Papers*, U.S. Government Printing Office, Washington, D.C., November 1969.

Table 7.1

ESTIMATED FINANCIAL ASSISTANCE AND SOCIAL SERVICE EXPENDITURES
FOR HANDICAPPED YOUTH, 1970

Program	Financial Assistance			
	Federal	State	Local	Total
SSDI	\$ 10,936,000	\$ 0	\$ 0	\$ 10,936,000
AB	3,190,000	1,940,000	420,000	5,550,000
APTD	20,110,000	12,750,000	3,330,000	36,190,000
AFDC ^b	311,346,000	205,046,000	64,476,000	580,868,000
GA	0	NE ^a	NE	NE
ITEB	1,000,000	NE	0	1,000,000
Total	\$346,582,000	\$219,736,000	\$68,226,000	\$634,544,000

SOURCE: See subsection "Current Financial Assistance Programs" in this section for data sources and estimation methods.

^aNot estimated, but assumed to be a small portion of total expenditures for financial assistance to handicapped youth.

^b1971.

Table 7.2

ESTIMATED NUMBER OF YOUTH RECEIVING
FINANCIAL ASSISTANCE, 1970

Program	Number of Handicapped Youth
SSDI	14,700
AB	4,000
APTD	29,000
AFDC	975,920 ^a
GA	NE ^b
ITEB	9,000

SOURCE: See subsection, "Current Financial Assistance Programs," in this section for data sources and estimation methods.

^a1971.

^bNot estimated, but assumed to be a small fraction of the total number of handicapped youth receiving long-term financial assistance.

cluded that present levels are inadequate and that the present distribution of aid is inequitable. In brief, the Federal Government acquired its present role because it had the funds and the inclination to distribute them to the needy population across states more equitably and to raise the payments to a more nearly adequate level. Although state and local roles have gradually diminished, both state and local governments are still very much involved, supplying nearly half the funds expended for needy handicapped youth, and operating both the General Assistance and the Aid to Families with Dependent Children programs.

Table 7.3

ESTIMATED FINANCIAL ASSISTANCE TO YOUTH
BY TYPE OF HANDICAP, 1970

Handicap	Estimated Expenditures
Visual impairment	\$ 18,276,000
Hearing impairment	24,902,000
Speech impairment	203,993,000
Crippling and other health impairments ...	95,620,000
Mental retardation	160,532,000
Emotional disturbance	88,027,000
Learning disability	<u>43,194,000</u>
Total	\$634,544,000

SOURCE: See subsection "Current Financial Assistance Programs" in this section for data sources and estimation methods.

The Federal Social Security Insurance program (OASDHI) is based on a social insurance model wherein an employee, his employer, and self-employed persons contribute to the system to provide coverage against disruption or reduction of the worker's income due to disability, death, or retirement. Payments are not based on need, but depend on the rate and number of quarter-years of previous contribution to the system, subject to maximums and minimums. Under the Childhood Disability provisions of this program, a person age 18 or older, who has been disabled prior to his 22nd birthday, and who is the child or grandchild of a retired or disabled worker, could receive payments of up to \$166 per month beginning September 1972, while the disabled child or grandchild of a deceased worker could receive up to \$256.90 beginning September 1972, if he earns \$125 or less per month. Because handicapped youth under age 22 have generally neither accumulated the required previous earnings record, nor have a retired, disabled, or deceased parent, only a small fraction actually receives benefits from this program; an estimated 14,700 recipients under 22 receive approximately \$62 per month each.

Prior to 1972, the AB and APTD public assistance programs were operated within the states and jointly funded by Federal and state governments. The Social Security Act of 1972 combined these two programs with Old Age Assistance (OAA) and made the new combined program federally funded and operated effective in 1974. The new program, called Supplemental Security Income (SSI), establishes uniform payment levels for recipients in all 50 states and the District of Columbia. (Individual states may choose to supplement these Federal payments.) Eligibility requirements for new applicants are also uniform and not based on age. This uniformity contrasts with previous requirements which varied from state to state. However, individuals on the AB and APTD rolls for December 1973 under a state plan in effect as of October 1972 will be considered blind or disabled for purposes of the new program and will be considered to meet the resource requirements of the new program. (The blind will also be deemed to meet the income test.) These persons will be transferred to the SSI rolls January 1, 1974 if they also meet the other requirements of Title XVI such as income (not required of the blind), age, relationship, etc.

New applicants must meet all requirements of the new program. For an applicant to qualify for payments under the new program, based on a disability other than visual, he must meet the income and resources test and be unable to engage in any substantial gainful activity by reason of a medically determinable physical or mental impairment which can be expected to result in death, or which has lasted (or can be expected to last) for a continuous period of not less than 12 months. A child's (age under 21) income and resources include those of his parents or his parent's spouse, if his parent or parent's spouse lives with him, whether or not they are available to him, except to the extent determined to be inequitable. Visually handicapped applicants must meet the income and resources test and must have a medically determinable impairment (e.g., central visual acuity of 20/200 or less in the better eye with the use of a correcting lens). Ability to engage in a substantial gainful activity is not a factor in determining eligibility for the blind.

Payments for an eligible individual who does not have an eligible spouse will be at the rate of \$130 per month in 1974 and any year thereafter, reduced by the amount of the individual's non-excludable income. Payments for an eligible individual who has an eligible spouse will be at the rate of \$195 per month in 1974 and, thereafter, reduced by the amount of the individual's non-excludable income (combined with that of his spouse). These payment levels are higher than the old program payment levels in most states, and any state may supplement the Federal payment level if desired.

Under the pre-1972 AB program, the average monthly grant varied from \$59 in one state to \$177 in another, with a United States average of \$104. Coupled with varying payment levels were varying eligibility standards by age (5 years in one state, 18 years in many others), by whether or not property liens were required, and by the allowable value of home and personal possessions. Five percent of all AB recipients were under 22. In 1970, we estimated that there were 4076 recipients under 22 on whom a total of \$5,550,000 was expended. The annualized expenditures per recipient varied across the states from \$714 to \$2058 and averaged \$1372. The number of recipients per 100,000 state population aged 0-21 varied from 0.5 to 19. The fraction of total program expenses devoted to administration, service, and training (A,S&T) rather than financial assistance varied across states from 5 to 32 percent.

The APTD program had a U.S. average monthly recipient grant of \$97 in 1970. Total annual expenditures per recipient averaged \$1229, but varied across states from \$724 to \$1837. A total of 29,000 persons aged 22 or less that year received APTD, or 3.4 percent of all APTD recipients. Age requirements were uniform across states at 18 years, but other eligibility requirements varied markedly. The number of recipients aged 18 to 21 per 100,000 state population averaged 205, but ranged from 27 to 625. Perhaps the most graphic example of the inequity of the payments distribution is the fact that nearly half of all APTD payments to recipients under 22 in 1970 were paid in California.

The AFDC program provides financial assistance to needy families with children, and to handicapped children only if they happen to be in an AFDC recipient family. In March 1971, the average monthly payment was \$49.60 per recipient. However, the program is so large that an estimated \$580,868,000 was expended on 975,920 handicapped youth in 1970. This is by far the most massive financial assistance program serving handicapped youth, and an excellent contact point for identi-

ying those who need nonfinancial types of assistance. Now that the new Supplemental Security Income program reaches handicapped youth, care must be taken in writing administrative rules and regulations so that a child's receipt of Aid to the Blind and Disabled does not exclude the remainder of the family from AFDC, and vice versa.

General Assistance is a state-local program with eligibility based on financial need. Although information is not readily available, we suspect very few handicapped youth receive long-term GA because of the incentive for states to place such youth on AB, APTD, or AFDC where Federal funding can be obtained.

In a survey of state welfare agencies, problems cited in the present system included lack of financial support for the programs and inadequate coordination of services.

In summary, we have six principal observations on financial assistance programs for handicapped youth.

1. There was no financial assistance program for handicapped youth prior to the Social Security Amendments of 1972 that removed age restrictions on Aid to the Blind and Disabled. Those prior assistance programs aimed at the handicapped did not serve persons less than 16 or 18 in most states. The AFDC assistance program for needy families with children is designed for the needy and not the handicapped, so allowance is not made for the added expense of the handicapped child for those families who do receive AFDC. The individual payment level of the new Supplemental Security Income program providing aid to the aged, blind, and disabled is significantly higher than the AFDC average payment.
2. The fact that the AFDC and other programs annually contact approximately one million handicapped children represents a great opportunity to screen and identify handicapping conditions in that population and to determine whether nonfinancial assistance needs are being met. Early medical intervention, provision of sensory aids, or assistance with language development for deaf children may be especially important.
3. Financial assistance programs do not reach out to find handicapped people. Financial aid is given to needy families with handicapped youth who ask for aid, not necessarily to those with the greatest need.
4. Inequity in payment levels and eligibility requirements exists across states. The new federally administered and combined Supplemental Security Income program corrects many of the former inequities in these three programs.
5. Although many authorities feel the present payment levels are inadequate, they have neither agreed upon definitions of adequacy and payment levels necessary to provide a socially acceptable standard of living nor studied them in the depth warranted by the importance of the topic.
6. Program evaluation data are woefully inadequate. The estimates of handicapped or other subpopulations reached must be based on rather tenuous assumptions; knowledge of social and other services delivered is scant; and knowledge of the actual effects that the financial assistance program has on the recipients is a small fraction of what it should be.

ROLES AND GOALS

The Federal Role and Objectives

Through a history of legislation which began in 1935, the Federal Government has accepted partial responsibility for assuring Americans some measure of economic security. One means is through programs affecting individual income levels. Such programs include those aimed at human resources development, such as Adult Basic Education; social insurance, in particular Old Age, Survivors, Disability, and Health Insurance (OASDHI); cash transfer programs, which include public assistance and veterans' pensions; and income-in-kind transfer programs, the most well known being the Food Stamp Program and Medicare. In addressing income maintenance, we look principally in this section at programs involving cash transfers as these specifically affect the handicapped.

Originally, the Social Security Act provided for Federal funds to assist states in providing income to the needy aged, the blind, and families with dependent children. In 1950, permanently and totally disabled persons were added to the federally supported program.² In the late 1950s, the Federal Government began using funds for administration and social service expenses associated with income maintenance programs. The 1972 Social Security Act Amendments represent a significant change in role in that the Federal Government is taking over operation of Aid to the Aged, Blind, and Disabled programs from the states and establishing uniform payment levels and eligibility standards across states under the Supplemental Security Income program. It also removes the minimum age restrictions on recipients. Thus, in 37 years the Federal Government has taken the dominant role in financing and operating income maintenance programs for needy handicapped persons; i.e., it finances and delivers income payments to (1) needy physically and mentally impaired persons, and (2) children who incidentally may be handicapped but receive aid because their families qualify for AFDC.

The President's Commission on Income Maintenance Programs presented the following concepts for evaluating transfer programs:³ clearly defined rights for potential participants; adequate cash payment to achieve socially desired income distributions; equity for both recipients and nonrecipients; minimum adverse incentives; and low administrative costs. These evaluation concepts are consistent with those of this research project.

In evaluating existing programs against these criteria, the Commission concluded that a new income maintenance program was needed because poverty had not been eliminated under the existing three-part system (built on the ideas that employment would provide adequate income to those who worked, social insurance would assist those forced out of jobs, and residual aid would go to those who were unemployable). The Commission called for a new program that the Federal Government would finance and administer. A start toward this new program are the recently passed Social Security Act Amendments of 1972 which incorporate some (but by no means all) of the Commission's recommendations.

The main problem in dealing with the goals of income maintenance programs

² For a more detailed picture, see *The President's Commission on Income Maintenance Programs*.

³ *Ibid*, pp. 3-6.

is one of defining "need" and "adequate" income. Most states have a nebulous definition of need that typically includes words like "sufficient income or other resources to provide a reasonable subsistence compatible with decency and health." This general definition is then translated into dollar terms, often without real knowledge of what various income levels mean in terms of the goods and services that can be purchased.

Another example of a nebulous social welfare goal comes from the social service area in which the stated Federal objective is "to provide social services to needy individuals . . . services are directed toward assisting individuals to attain or retain self support and self care and to maintain and strengthen family life."⁴

Models, Functions, Rationales, and Processes

Referring to the discussion in Sec. 3 of the functions, rationales, and processes by which policies have been created and implemented, it is clear that since 1935 the Federal Government's welfare role has evolved in an unmistakable trend toward being one of direct operation. The 1972 Social Security Act Amendments continue and strengthen that trend by giving operation of the Aid to the Aged, Blind, and Disabled programs to the Federal Government under the Supplemental Security Income program. This trend, however, is not in accordance with current Presidential Initiatives that appear to redefine and restructure the Federal role in domestic programs.

If the Controllership model were applied to welfare, it is apparent that primary Federal activity in the functional areas of research and development, demonstrations and social experiments, data collection and accounting, and evaluation must be strengthened while the historical tendency to provide direct financial assistance to individuals will diminish. One must stress the need to refrain from "going out of business" altogether at the Federal level, even if the nature of the "business" itself changes in the general ways we characterize.

Two dominant rationalizations have operated historically that account for the Federal welfare trend toward direct operation. Insufficient state and local resources have certainly been at the root of and have justified many Federal policies, but this rationale becomes less viable as revenue sharing redistributes resources back to local authorities. The balance wheel rationale should continue to be viable as more authority and responsibility are shifted back to the states to deliver and account for specific services and programs, because revenue sharing may redistribute funds across the states. Economies of scale arguments to the effect that centralized Federal responsibility reduces bureaucratic overheads attendant to the administration of income maintenance programs also seem less viable if the focus of service delivery and responsibility were to be decentralized and shifted to the state and local levels.

In the remainder of this subsection we review existing Federal and state income maintenance programs; examine the population serviced and what portion of it is composed of handicapped youth; indicate problems inherent in the present system;

⁴ *Catalog of Federal Domestic Assistance, Executive Office of the President, Office of Management and Budget, November 1972.*

and review services other than income maintenance that are financed by social welfare agencies.

CURRENT FINANCIAL ASSISTANCE PROGRAMS

The Social Security Insurance System

The Social Security Insurance system is based upon a social insurance model of income transfer. The worker, his employer, and self-employed persons are taxed to finance the system of Old Age, Survivors, Disability, and Health Insurance. In return, the worker is covered against certain types of economic risk—disruption or reduction of income due to death, disability, or retirement. If a person covered by Social Security becomes disabled or attains retirement age, he and certain dependent relatives are entitled to benefits, and if he dies, certain surviving relatives are entitled to benefits. Children receive benefits to age 18 (to age 22 if full-time students) regardless of whether or not they are disabled. Need or financial condition is *not* a factor in determining eligibility. The monthly amount of the benefit is based largely on the rate at which contributions were made (a function of earnings) and the number of quarters during which contributions were made, subject to minimums and maximums. The overall benefits for the Social Security system are established and changed by Congressional legislative action.

The amount of work a person needs to be eligible for benefits depends on the age when he became disabled:⁵

1. A person disabled before age 24 needs credit for 1-1/2 years of work in the 3-year period ending when his disability begins.
2. A person disabled at any time from age 24 through 30 must have worked half the time between age 21 and the date he became disabled.
3. A person disabled at age 31 or older needs credit for at least 5 years of work out of the 10 years ending when he became disabled. Some workers may need more credit depending on their age.

A blind person does not have to meet the above provisions if he is fully insured. The number of quarters required to be fully insured ranges from a minimum of 6 to a maximum of 40, depending upon the year disability began and the age of the disabled person in that year.

Retired workers and their eligible dependents can receive benefits if the retired worker was fully insured, and survivors of deceased workers can receive benefits if the worker was either fully insured or currently insured. (To be currently insured

⁵ U.S. Department of Health, Education and Welfare, *The Benefit Provisions of the Old Age, Survivors, Disability and Health Insurance System*, Social Security Administration, DHEW Publication No. SSA 72-11500 (8-71), April 1971; and the U.S. Department of Health, Education and Welfare, *Social Security Programs in the United States*, Social Security Administration, March 1968; and letter from F. L. Lunsford, Chief, Rehabilitation Planning and Coordination Branch, Social Security Administration, to J. S. Kakalik, The Rand Corporation, June 1, 1973.

a worker must have credit for 1-1/2 years of work during the 3 years immediately preceding death.)

Under the Childhood Disability Beneficiary Program, the Social Security Act provides for benefits to handicapped youth who are dependents of the adult worker. To qualify for benefits under this program a person must (1) be the son or daughter of an insured worker who is retired, deceased, or disabled; (2) be at least 18 years of age or older; and (3) have been continuously disabled prior to his 18th birthday.⁶

The definition of disability for a child is the same as for a disabled worker, i.e., the individual must be unable to engage in any substantial gainful activity by reason of a medically determinable physical or mental impairment that can be expected to result in death or that has lasted or can be expected to last for a continuous period of at least one year. Under the Social Security disability program, earnings exceeding \$140 a month have been established as an indication of substantial gainful activity, and an individual who derives such earnings on the basis of his service is usually not considered disabled within the meaning of the Social Security Act. Under the definition, substantial gainful activity means the performance of significant duties over a reasonable period of time in work for remuneration or profit or in work of a type generally performed for remuneration or profit.

The Social Security Administration, at the present time, has agreements with 54 state agencies to carry out vital functions in the development and evaluation of disability claims. All but six of these state agencies operate under a vocational rehabilitation plan. These six are either independent agencies or operate under umbrella agencies. Whether the disability determination is made by a VR agency or another state agency, every disability determination includes an evaluation of vocational rehabilitation potential, and persons who can reasonably be expected to benefit from vocational rehabilitation are referred for services.

Additionally, Titles XVI and II provide for reimbursement of VR agencies for rehabilitation services rendered for Supplemental Security Income recipients and selected Social Security disability beneficiaries.

Disability determinations are reviewed by the Social Security Administration's national office in Baltimore to assure consistency and conformity with national regulations. Benefits to a childhood disabled beneficiary are paid on the basis of the father's or mother's work record and earnings account. The benefit level varies depending on the parent's work history and also on whether the parent's status is deceased, retired, or disabled. In 1970, for example, the maximum benefit was \$125.40 per month if the parent was retired or disabled and \$188.10 if the parent was deceased.

The 1966 Social Security Survey of the Disabled⁷ revealed that the population of childhood disability beneficiaries had approximately the same distribution with respect to sex as the general population—half were men and half were women. The median age was 37, and more than 75 percent had completed less than 8 years of school. Few had any current employment, and five out of six had never been em-

⁶ The Social Security Amendments of 1972 changed this to 22 years, the change becoming effective in January 1973.

⁷ L. D. Haber, "The Disabled Beneficiary—A Comparison of Factors Related to Benefit Entitlements," *Social Security Survey of the Disabled, 1966*, U.S. Department of Health, Education and Welfare, Social Security Administration, Office of Research and Statistics, Report 7, June 1969.

ployed. For most of this group, Social Security benefits were the principal source of income.

We estimate that approximately 14,700 individuals aged 18-21 receive childhood disability benefits in any one year.⁸ In 1968, approximately 245,000 childhood disability beneficiaries received \$15.1 million in monthly benefits. This is an average of \$62 per month per recipient or \$744 annually. Applying this annualized figure to our above estimate gives a conservative estimate of \$10,936,000⁹ in money payments per year from the childhood disability program to youth aged 18-21. The breakdown by type of handicap¹⁰ is approximately 1 percent visual impairments, 2 percent hearing impairments, 54 percent mental retardation, 15 percent mental illness, 4 percent orthopedic impairments, and 24 percent other health impairments.

Public Assistance

In addition to the OASDHI, the Social Security Act also provides for Federal funds for money payments, medical care and social services for persons who are aged, blind, totally and permanently disabled, and low income families with dependent children. These public assistance payments are based on financial need and not conditioned on the recipient having worked and paid into the system a certain number of quarters. *Thus, the model is one of "payments to the needy" rather than one of "insurance."*

Prior to 1972, Federal grants for money payments were made available to states on a matching basis under four separate categories of public assistance programs or under a single combined program depending on the administering state's agency structure. That is, monies were available under Old Age Assistance, Aid to the Blind, Aid to the Permanently and Totally Disabled, and Aid to Families with Dependent Children, or under a program that combined the first three types of public assistance. As of June 1970, 32 states maintained four separate programs, while 18 had combined programs.¹¹

In the administration, organization, and conduct of the public assistance programs prior to 1972, the Federal Government established guidelines and requirements within which the states developed and administered their own public assistance programs. The states set varying eligibility requirements as well as amounts of the assistance payments. Each state defined its own minimum standard of living, which was used in determining individual or family need. Summaries of some of the state requirements are shown in the following subsections.

⁸ Approximately 20,000 new childhood disability cases are approved annually. Of these new recipients, 50 percent are aged 18-24. Assuming these to be evenly distributed across ages, on the average 1470 are in each age—18, 19, etc. Accumulating new recipients and those registered in previous years gives the estimate of 14,700 aged 18-21.

⁹ It is estimated that 13,000 additional people became eligible for childhood disability benefits as a result of the age change in the 1972 Social Security Amendments. This group has not been included in the above estimates as no information on them is available. U.S. Congress, Joint Committee on Ways and Means, *Summary of Social Security Amendments of 1972 as Approved by the Conferees*, 92d Cong., 2d Sess., H.R. 1, October 17, 1972, p. 3.

¹⁰ *Social Security Disability Applicant Statistics*, Social Security Administration Publication 35-71 (5-71), pp. 80-81.

¹¹ U.S. Department of Health, Education and Welfare, *Characteristics of State Public Assistance Plans Under the Social Security Act, 1970 ed.*, Social and Rehabilitation Service, Public Assistance Report No. 50, June 1, 1970.

As a result of the Social Security Amendments of 1972, the system of income maintenance for the aged, blind, and disabled is undergoing massive change. As mentioned earlier, income maintenance for these three groups, which was funded partially by the Federal Government and organized and administered by the states, will now be administered completely by the Federal Government under the Social Security Administration (SSA). The new program will establish a federally determined full standard payment, thereby replacing the 50 different ones previously determined by the states. In placing the program under SSA, recipients will no longer have to apply for assistance at both the Social Security Office (if applicable) and at the State Welfare Office. By eliminating this duplication, the new system will reduce the number of people needed to administer these programs. Only poor families with children, receiving aid under AFDC, will remain on the federally supported welfare programs run by the counties or the state after the new SSA program begins. The target date for the new program is January 1, 1974. For the conversion, pattern setting programs are being set up in Los Angeles County and in four states—Missouri, Florida, Ohio, and Wisconsin.

Under the new Supplemental Security Income program, an eligible aged, blind, or disabled individual who does not have an eligible spouse may receive up to \$130.00 per month in 1974, and thereafter; and an eligible individual with an eligible spouse may receive up to \$195.00 per month in 1974, and thereafter. If they wish, states can provide payments to individuals who, because of income or resource limitations, do not qualify for Federal payments. Recipients of Federal program assistance will be allowed to have a home, personal property, and life insurance up to a reasonable value, to be determined. In determining a person's eligibility to receive Supplemental Security Income payments, certain income is disregarded. The first \$65 of earned income is disregarded as well as an additional \$20 of either earned or unearned income.

A few states now pay more than the newly established Federal minimum. These states or any others may choose to supplement the Federal welfare payment either by entering into agreement with HEW such that the Federal Government administers the state supplemental program, or by administering their own supplemental payments program.

To allow for orderly transfer from the existing AB and APTD programs to the SSI program, persons receiving AB or APTD for December 1973 under state plans in effect as of October 1972 will be deemed to meet the definitions of blindness or disability as well as the resources requirement of the new program. (The blind will also be deemed to meet the income test.) New applicants must be blind or disabled as defined under the new program, must meet the SSI income and resources test, and must meet all other requirements of the SSI program to qualify for monthly payments. In defining blind, for example, the law states two definitions. The first is that "An individual should be considered to be blind . . . if he is blind as defined under a State plan approved under Title X or XVI as in effect for October 1972 and received aid under such plan for December 1973. . . ."¹² The second definition is the standard "legal blindness" definition relating to visual acuity and limited field of vision and applies to individuals not currently covered by a state plan.

It is important to note how this second definition contrasts with the definitions given for other types of disability related to physical and mental condition, which

¹² P.L. 92-603, *Summary of Social Security Amendments of 1972*, pp. 143-144.

have an important work related clause. That is, disabled is defined as unable to engage in any substantial gainful activity by reason of physical or mental impairment. This is further amplified by a subsequent paragraph stating that "an individual shall be determined to be under a disability only if his physical or mental impairment or impairments are of such severity that he is not only unable to do his previous work but cannot . . . engage in any other kind of substantial gainful work. . . ."¹³ This difference in definitions existed under the old law and has been carried over to the new one.¹⁴ It suggests that visual impairment automatically precludes substantial gainful work and it is not clear that this is in fact the case. The question to be asked is why, if blind, one must be blind and needy to qualify whereas, if disabled, one must be disabled, needy, *and* unable to work.

Initial estimates show an additional total caseload of 2.8 million persons on the Supplemental Security Income program in 1973. With the 3.4 million estimated to be eligible in that year under existing state plans, this makes a total of 6.2 million cases. In addition, it is estimated that by 1977 these figures will have grown to 7.2 million, just twice the number that would have been served had the old program continued.¹⁵

It is estimated that shifting the income maintenance program from the states to the Federal Government will save the states \$1.6 billion¹⁶ in 1973. A breakdown of these changes is shown below in costs per \$ billion. These figures are for AFDC, AB, APTD, and CAA. They show that in 1973, HEW estimates that under existing law, state and local governments will spend \$5.1 billion as their share of assistance on the above four programs; under the new law, H.R. 1, their expenses for these same four programs would be only \$3.5 billion. This is assuming that all states maintain current assistance levels. Therefore of the total program increase of \$5.5 billion in Federal welfare expenditures, \$3.9 billion represents increased program costs and \$1.6 billion represents a replacement of state funds with Federal funds.

	Total Cost (\$)	Federal Cost (\$)	State and Local Cost (\$)
Present law	14.5	9.4	5.1
New law (H.R. 1)	<u>18.4</u>	<u>14.9</u>	<u>3.5</u>
Change	+3.9	+5.5	-1.6

It is hoped that the new program will eliminate some of the problems of inequity in grants and qualifications across states. With the new program now a matter of law, criticism of the old program serves little purpose; however, we describe the old AB and APTD income maintenance programs in some detail, since the clients of the old program are also the first clients of the new one. In addition, we highlight some of the problems associated with the old program so that they may be avoided under the new program.

The next three subsections describe the former AB and APTD programs, and the unchanged current AFDC program, respectively.

¹³ P.L. 92-603, *ibid*.

¹⁴ *Social Security Programs in the United States*, pp. 28, 29.

¹⁵ U.S. Senate, Committee on Finance, Russell B. Long, Chairman, Material related to H.R. 1, *Aid to the Aged, Blind and Disabled; Social Services; Fiscal Relief for States*, 92d Cong., 1st Sess., U.S. Government Printing Office, Washington, D.C., 1971.

¹⁶ *Ibid.*, p. 19.

Aid to the Blind. All states have Aid to the Blind programs. In 32 states these are separate programs; in 18 they are combined with APTD and OAA. Twenty-nine states have no age requirement, whereas the others require a minimum age of 16, 18, or 21 (Kansas is the only exception with an age 5 requirement). The average monthly grant in the United States in 1970 was \$104, with average state grants ranging from \$177 in Alaska to \$59 in Mississippi. Eighteen states placed liens on property, 12 limited the value of the recipient's home, and nearly all limited possession of personal property to \$2000 or less. These and other program characteristics are shown in Table 7.4. Note the large variations in both eligibility requirements and payment levels across the states.

Federal participation in assistance payments can be computed by applying either the formulas specified in the money payment titles of the Social Security Act or by applying the Federal medical assistance percentage to total payments in states operating a medical assistance program under Title XIX of the Social Security Act. Under the first system (often referred to as the two-step formula method or more simply the "formula" method), the Federal share of assistance payments for AB, OAA, and APTD was 31/37 of the first \$37 of the average monthly payment per recipient times the number of recipients, and from 50 to 65 percent of the state's average assistance payment that exceeds \$37 times the number of recipients. The maximum Federal payment under both parts of the formula is \$75 times the number of recipients.

States operating an approved medical assistance program under Title XIX of the Social Security Act may use an alternate method for computing the Federal share of money payments. The Federal share is computed by applying the Federal medical assistance percentage to the aggregate amount spent for money payments for AB, OAA, APTD, and AFDC. There is no maximum on the amount the state spends. The percentage applied against this amount is from 50 to 83 percent, depending on a state's per capita income. This second method is simpler and potentially more generous than the formula method. As of July 1971, 29 states were using the alternate method.

The most recent survey of AB recipients for which detailed data are available was completed in June of 1970.¹⁷ In that month, 78,703 persons received an assistance payment from a Federal-State Aid to the Blind program. Of this total, 1580 or 2 percent were under 18, and an estimated 4076 or 5 percent were under 21. In other terms, a total of about 5 per 100,000 youth in the 0-21 age range in the general population received AB. The estimated monthly grants for young AB recipients was \$423,900 in June 1970. These data are shown for individual states in Table 7.5.

Compared to the nation as a whole, some states show marked variation in age group participation in AB programs. Young persons constitute 1 to 12 percent of AB recipients, depending on the state. The recipient rate per 100,000 state population aged 0-21 varied from 0.5 to 19 per 100,000. Notice, for example, that in Oregon the program serves 610 people (0.03 percent of the state's population), and approximately 6 percent of these are in the 0-21 age group. Alternatively, Virginia serves 1200 persons or 0.02 percent of its population, and only 1.0 percent of these are aged 0-21. Both programs appear similar in terms of the characteristics shown in Table 7.4.

¹⁷ U.S. Department of Health, Education and Welfare, *Findings of the 1970 AB Study, Part I. Demographic and Program Characteristics*, Social and Rehabilitation Service, DHEW Publication No. (SRS) 73-03903, September 1972.

Table 7.4

SELECTED CHARACTERISTICS OF STATE AID TO BLIND PROGRAMS^a

State	Average Monthly Grant 12/70 ^b	Maximum Monthly Payment	Separate or Combined Program	Age Requirement	Property Liens	Allowed Value of House	Personal Property Limit
United States	\$104						
Alabama	70	\$ 75	S	16+	No	NS ^c	\$1200
Alaska	177	200	C	18+	Yes	NS	1000
Arizona	81	None	S	16+	No	8,000	800
Arkansas	80	94	C	16+	No	4,500-6,000	500
California	160	202	S	16+	No	NS	1500
Colorado	89	None	S	None	Yes	NS	1000
Connecticut	101	None	S	None	Yes	NS	600
Delaware	110	None	S	18+	No	NS	1500
Florida	75	90	C	None	Yes	NS	600
Georgia	67	87	C	16+	No	NS	800
Hawaii	130	None	C	None	No	25,000	---
Idaho	84	None	S	None	No	NS	750
Illinois	93	None	C	None	Yes	NS	400
Indiana	72	95	S	18+	Yes	NS	350
Iowa	122	None	S	18+	No	NS	1500
Kansas	79	None	C	5+	Yes	---	500
Kentucky	75	None	C	None	No	NS	2000
Louisiana	77	101	S	None	No	5,000	1750
Maine	88	115	C	16-65	Yes	NS	500
Maryland	94	None	C	None	Yes	NS	300
Massachusetts	151	None	S	18+	No	NS	2000
Michigan	106	None	S	16+	No	NS	750
Minnesota	101	None	S	None	Yes	NS	2000
Mississippi	59	None	S	None	No	2,500	500
Missouri	91	90	S	18+	No	NS	2000
Montana	94	None	S	None	Yes	4,999	500
Nebraska	93	None	C	16+	Yes	3,000	750
Nevada	92	None	S	None	No	NS	1500
New Hampshire	169	None	S	None	No	1,500	300
New Jersey	100	None	S	18+	No	NS	---
New Mexico	78	None	C	None	No	NS	1200
New York	136	None	C	None	Yes	NS	NS
North Carolina	85	None	C	None ^d	No	NS	600
North Dakota	104	None	C	None	Yes	NS	1000
Ohio	75	None	S	18+	No	NS	300
Oklahoma	106	127	C	None	No	8,000	350
Oregon	104	None	S	None	No	NS	500
Pennsylvania	121	105	S	21+	Yes	5,000	5000
Rhode Island	85	None	C	None	No	NS	1000
South Carolina	67	95	S	None	No	NS	750
South Dakota	96	None	S	18+	No	NS	1000
Tennessee	70	97	S	None	No	9,000	500
Texas	79	114	S	18+	No	NS	1800
Utah	87	86	S	None	Yes	NS	600
Vermont	102	None	C	None	Yes	NS	900
Virginia	86	None	S	None	No	NS	400
Washington	98	None	S	16+	No	NS	750
West Virginia	69	165	S	None	No	NS	1000
Wisconsin	91	None	S	None	Yes	NS	750
Wyoming	(d)	104	S	None	No	3,000	500

^a Source for all information except average monthly grant is U.S. Department of Health, Education and Welfare, *Characteristics of State Public Assistance Plans Under the Social Security Act, 1970 ed.*, Social and Rehabilitation Service, Public Assistance Report No. 50, June 1, 1970.

^b U.S. Department of Health, Education and Welfare, *Graphic Presentation of Public Assistance and Related Data, Demographic and Program Characteristics, Financial Characteristics of Recipients, 1971*, Social and Rehabilitation Service, DHEW Publication No. (SRS) 73-03101, October 6, 1972.

^c Not specified.

^d Fewer than 50 recipients.

Table 7.5

AID TO BLIND RECIPIENTS, BY AGE

State	No. of AB Recipients		Age 0-21 Recipients:		Total Monthly Grants to Aged 0-21 Recipients ^c
	All Ages ^a	Aged 0-21 ^b	As Percent of All Recipients	As Percent of Total Population Aged 0-21	
U.S. total	81,000	4,076	5.0	0.005	\$423,900
Alabama	1,900	120	6.3	0.008	8,400
Alaska	94	(d)	---	---	---
Arizona	530	---	---	---	---
Arkansas	1,700	73	4.3	0.009	5,840
California	14,000	1,008	7.2	0.013	161,280
Colorado	230	6	2.5	0.0006	534
Connecticut	250	---	---	---	---
Delaware	380	9	2.3	0.0038	990
Florida	2,300	184	8.0	0.0073	13,800
Georgia	3,200	138	4.3	0.0069	9,246
Hawaii	73	---	---	---	---
Idaho	100	---	---	---	---
Illinois	1,700	22	1.3	0.0005	2,046
Indiana	1,300	18	1.4	0.0008	1,296
Iowa	1,200	31	2.6	0.0027	3,782
Kansas	420	---	---	---	---
Kentucky	2,100	260	12.4	0.019	19,500
Louisiana	2,400	274	11.4	0.016	21,098
Maine	230	14	6.3	0.003	1,232
Maryland	350	---	---	---	---
Massachusetts	2,800	78	2.8	0.003	11,778
Michigan	1,400	76	5.4	0.002	8,056
Minnesota	860	---	---	---	---
Mississippi	2,200	264	12.0	0.003	15,576
Missouri	4,000	92	2.3	0.005	8,372
Montana	190	---	---	---	---
Nebraska	320	---	---	---	---
Nevada	170	10	6.0	0.005	920
New Hampshire	220	---	---	---	---
New Jersey	1,000	27	2.7	0.001	2,700
New Mexico	370	---	---	---	---
New York	3,800	156	4.1	0.002	21,216
North Carolina	4,500	320	7.1	0.015	27,200
North Dakota	82	---	---	---	---
Ohio	2,700	70	2.6	0.002	5,250
Oklahoma	1,300	75	5.8	0.007	7,950
Oregon	610	36	6.0	0.0005	416
Pennsylvania	7,900	87	1.1	0.002	10,527
Rhode Island	120	---	---	---	---
South Carolina	1,900	53	2.8	0.005	3,551
South Dakota	120	---	---	---	---
Tennessee	1,700	156	9.2	0.010	10,920
Texas	4,000	112	2.8	0.002	8,848
Utah	160	---	---	---	---
Vermont	110	---	---	---	---
Virginia	1,200	12	1.0	0.006	1,032
Washington	480	22	4.6	0.002	2,156
West Virginia	550	12	2.1	0.002	828
Wisconsin	690	77	11.1	0.004	7,007
Wyoming	34	---	---	---	---

^aDecember 1970 data from Department of Health, Education and Welfare, Social and Rehabilitation Service Publication "Welfare in Review."

^bU.S. Department of Health, Education and Welfare, *Findings of the 1970 AB Study, Part I. Demographic and Program Characteristics, Social and Rehabilitation Service*, DHEW Publication No. (SRS) 73-03903, September 1972. Estimated by adding the actual number of recipients aged 0-17 plus 4/7 of the actual number of recipients in the 7-year age range of 18-24 years.

^cEstimated by multiplying the number of aged 0-21 recipients by the average AB monthly grant in the state.

^dDash means that smaller table entries are missing where the 1970 AB survey results were not reported due to the statistical unreliability of the small sample.

What then are the reasons for such differences in numbers served when both states have much the same percentage of their population aged 0-21? Are the differences due to underlying population differences such that those young visually impaired persons in Oregon are more in need of assistance? Does it suggest that Virginia has an earlier identification and more successful rehabilitation program? Or does it suggest that Oregon has a more aggressive outreach program? These questions cannot be answered from the data available, but point out the need for more complete data.

Two important questions included in the 1970 AB survey were the following: (1) age at loss of sight, and (2) other aid received. Unfortunately, the data are not presented by recipient age. Because of the overall importance of these questions, however, it is worth reviewing the findings briefly, even though they are not age specific. Approximately 40 percent (for whom the age at loss of sight was known) lost their sight before 18; 25 percent were blind at birth; 67.7 percent received no assistance other than AB, while 29.9 percent received two or more types including OAA, APTD, AFDC, or state General Assistance.

More interesting is the comparison of administration, service, and training versus financial assistance costs in each state, as shown in Table 7.6. Some states spend nearly all the funds on financial assistance while others spend a substantially smaller proportion. For example, Arkansas reports administration, service, and training costs of 5.3 percent of total program cost while Indiana reports 23.7 and Ohio 31.8 percent. The A,S&T costs per recipient in Arkansas, Indiana, and Ohio are \$55, \$416, and \$406 per year, respectively, while the United States average is \$180. Reasons for the differences are not clear, but determining the causes of such variations seems worthy of further study.

Total AB expenditures per recipient in 1970 averaged \$1372 annually across the states, ranging from \$714 in Mississippi to \$2058 in California.

With approximately 5 percent of AB recipients under age 22, and assuming the same average expenditure per recipient regardless of age, we obtain an order of magnitude estimate of \$5,550,000 as the total annual expenditure for young AB recipients in 1970. The amount of Federal participation in support of these assistance payments is determined by one of the two methods explained earlier.

The high variance in Federal participation in administration and assistance is apparent from Table 7.6. Federal support of assistance payments varies from a high of 80.4 percent in Mississippi to a low of 40.9 percent for Alaska, the latter suggesting that Alaska is using the formula method. In addition, Alaska has a high average grant and so receives proportionately less Federal support. Mississippi, however, pays one of the smallest grants and hence receives the greater amount of Federal participation under either formula method. Of the \$5,550,000 annual expenditure in 1970, we estimate that the Federal, state, and local contributions were \$3,190,000, \$1,940,000, and \$420,000, respectively, using the United States averages presented in Table 7.6.

Aid to the Permanently and Totally Disabled. The APTD program grew rapidly from an initial caseload of 68,800 in December 1950 when the program began to 1,068,000 in December 1971. All states except Nevada have an APTD program. In 31 states these are separate programs, while in 18, APTD is combined with AB and OAA. All programs require a minimum eligibility age of 18. Average state grants range from \$56 (Louisiana) to \$177 (Alaska). The U.S. average monthly grant

Table 7.6
FINANCING OF STATE AID TO BLIND PROGRAMS, 1970

State	Number of Recipients, All Ages ^a	Administration, Service, & Training Expenditures ^b (A,S&T)				Financial Assistance ^c				Total Expenditures (\$000)				Assistance as Percent of Total AB Expenditures	A,S&T Expenditures per Recipient	Total Expenditures per Recipient
		Total (\$000)	Federal (%)	State (%)	Local (%)	Total (\$000)	Federal (%)	State (%)	Local (%)	Total	Federal	State	Local			
United States	81,000	14,643	56.9	30.4	12.7	96,460	57.5	35.6	6.9	111,103	63,772	38,834	8,497	86.8	\$180	\$1,372
Alabama	1,900	116	50.0	48.4	1.6	1,674	76.2	23.7	(d)	1,790	1,334	454	2	93.5	61	942
Alaska	94	21	55.9	44.1	---	144	60.9	59.0	---	165	71	94	---	87.3	223	1,755
Arizona	530	37	50.3	46.2	3.5	525	71.6	28.5	---	562	394	167	1	93.4	70	1,060
Arkansas	1,700	94	50.0	50.0	---	1,684	73.7	26.2	---	1,778	1,289	489	---	94.7	55	1,046
California ..	14,000	3,926	64.5	3.2	32.3	24,891	48.5	38.7	12.6	28,817	14,629	9,768	4,421	86.4	231	2,058
Colorado	230	32	66.0	17.3	16.7	199	62.8	17.0	20.1	231	146	40	45	86.1	139	1,004
Connecticut ..	250	50	61.0	39.0	---	284	47.8	52.4	---	334	166	168	---	85.0	200	1,336
Delaware	380	84	49.9	50.1	---	418	51.6	48.3	---	502	258	244	---	83.3	221	1,321
Florida	2,300	339	63.6	36.4	---	1,954	74.7	25.2	---	2,293	1,676	617	---	85.2	147	997
Georgia	3,200	248	60.2	33.7	6.1	2,439	69.5	26.0	4.4	2,687	1,846	718	123	90.8	76	840
Hawaii	73	13	52.7	47.3	---	96	48.9	51.0	---	109	54	55	---	88.1	178	1,493
Idaho	100	7	57.4	39.7	2.9	100	69.0	31.0	---	107	73	34	---	93.5	70	1,070
Illinois	1,700	278	55.4	44.6	---	1,919	52.5	47.4	---	2,197	1,162	1,035	---	87.3	164	1,292
Indiana	1,300	541	54.0	37.8	8.1	1,738	46.7	53.2	---	2,279	1,105	1,130	44	76.3	416	1,753
Iowa	1,200	249	61.2	37.3	1.5	1,649	55.3	22.3	22.3	1,898	1,064	462	372	86.9	208	1,582
Kansas	420	70	59.5	23.9	16.6	344	57.5	21.8	20.0	414	240	92	81	83.1	167	986
Kentucky	2,100	146	54.5	45.5	---	1,798	62.2	37.5	---	1,944	1,200	743	---	92.5	70	926
Louisiana ...	2,400	163	50.0	50.0	---	2,207	73.0	26.9	---	2,370	1,695	675	---	93.1	68	988
Maine	230	29	64.5	35.5	---	235	62.9	37.4	---	264	166	98	---	89.0	126	1,148
Maryland	350	44	59.6	32.1	8.3	375	56.2	32.0	10.4	419	237	138	43	89.5	126	1,197
Massachusetts	2,800	505	58.8	41.2	---	4,745	50.1	49.8	---	5,250	2,676	2,574	---	90.4	180	1,875
Michigan	1,400	145	50.0	48.9	1.1	1,619	50.0	50.0	---	1,764	882	881	2	91.8	104	1,260
Minnesota	860	184	62.6	7.9	29.5	882	57.0	22.3	20.8	1,066	618	211	238	82.7	214	1,240
Mississippi ..	2,200	142	50.0	47.3	2.7	1,429	80.4	19.5	---	1,571	1,220	347	4	91.0	65	714
Missouri	4,000	761	38.6	61.1	0.2	3,403	63.2	36.8	---	4,164	2,445	1,718	2	81.7	190	1,041
Montana	190	44	58.0	21.5	20.4	213	57.2	33.8	7.5	257	148	82	26	82.9	232	1,353
Nebraska	320	72	64.0	36.0	---	371	48.7	51.2	---	443	227	216	---	83.7	225	1,384
Nevada	170	96	68.2	31.8	---	198	53.0	47.4	---	294	170	124	---	67.3	565	1,729
New Hampshire	220	26	67.4	32.6	---	334	58.6	41.6	---	360	213	147	---	92.8	118	1,636
New Jersey ..	1,000	234	54.1	24.3	21.6	1,190	46.8	40.0	13.2	1,424	683	533	208	83.6	234	1,424
New Mexico ..	370	49	61.5	38.5	---	330	63.6	36.6	---	379	240	140	---	87.1	132	1,024
New York	3,800	1,502	55.1	28.8	16.1	5,281	49.8	25.2	24.8	6,783	3,461	1,766	1,556	77.9	395	1,785
N. Carolina ..	4,500	876	50.0	50.0	---	4,764	67.7	16.1	16.1	5,640	3,664	1,207	769	84.5	195	1,253
N. Dakota ...	82	20	62.1	14.8	23.1	97	70.1	25.7	3.0	117	80	29	8	82.9	244	1,427
Ohio	2,700	1,095	55.4	41.0	3.6	2,343	66.8	30.4	2.7	3,438	2,173	1,163	103	68.2	406	1,273
Oklahoma	1,300	86	50.0	50.0	---	1,652	53.7	46.2	---	1,738	931	807	---	95.1	66	1,337
Oregon	610	53	50.1	49.9	---	675	56.2	43.7	---	728	407	321	---	92.7	87	1,193
Pennsylvania	7,900	895	52.3	47.7	---	11,985	53.8	46.1	---	12,880	6,921	5,959	---	93.1	113	1,630
Rhode Island	120	20	58.0	42.0	---	105	51.4	49.5	---	125	65	60	---	84.0	167	1,042
S. Carolina ..	1,900	130	50.0	45.6	4.4	1,440	76.1	23.7	---	2,570	1,162	402	6	91.7	68	826
S. Dakota ...	120	23	54.3	42.7	3.0	111	69.3	29.7	---	134	90	43	1	82.8	192	1,117
Tennessee ...	1,700	118	55.0	41.9	3.1	1,527	74.3	20.2	5.0	1,645	1,205	359	81	92.8	69	968
Texas	4,000	167	50.0	48.7	1.3	3,764	70.9	28.9	---	3,931	2,756	1,173	2	95.8	42	983
Utah	160	24	64.3	34.9	0.8	154	64.2	35.0	---	178	115	62	---	86.5	150	1,113
Vermont	110	9	63.8	36.2	---	120	65.0	35.0	---	129	84	45	---	93.0	82	1,173
Virginia	1,200	247	58.8	17.1	24.1	1,014	64.6	21.7	13.0	1,257	802	263	192	80.4	206	1,048
Washington ..	480	43	55.6	44.4	---	528	48.6	51.3	---	569	280	289	---	92.8	85	1,185
W. Virginia ..	550	56	65.7	34.3	---	468	75.0	25.0	---	524	388	136	---	89.3	102	953
Wisconsin ...	690	273	49.7	39.9	10.5	666	54.6	24.9	20.1	939	500	275	163	70.9	396	1,707
Wyoming	34	11	62.7	10.9	26.4	31	67.7	29.0	---	42	28	10	3	73.8	324	1,235

^aData for December 1970 from Department of Health, Education and Welfare, Social and Rehabilitation Service Publication "Welfare in Review."

^bU.S. Department of Health, Education and Welfare, *Public Assistance: Costs of State and Local Administration, Services and Training, Fiscal Year Ended June 30, 1970*, National Center for Social Statistics, NCSS Report F-3 (FY 70).

^cU.S. Department of Health, Education and Welfare, *Source of Funds Expended for Public Assistance Payments and for the Cost of Administration, Services and Training, Fiscal Year Ended June 30, 1970*, National Center for Social Statistics, NCSS Report F-2 (FY 70).

^dBlanks indicate that local agencies supply no money.

was \$97 in 1970. Selected characteristics of the state APTD programs, Table 7.7, show that 22 states placed liens on property, 13 limited the value of the recipient's home, and nearly all limited personal property possession to \$2000 or less.

The most recent study of APTD recipients was done in June 1970.¹⁸ The median age of the 865,894 recipients was 54.6 years. Somewhat more than half of these were women—55.3 percent. Twenty-eight percent of the recipients had never been employed. Total recipients and recipients under age 22 are shown in Table 7.8. In 1970, an estimated 29,000 young persons received APTD, or 3.4 percent of the caseload for all ages.

As in AB, APTD programs vary greatly across states in eligibility requirements, payment levels, and the percentage of APTD recipients. Percentages, for instance, vary from 0.5 in New Hampshire to 6.6 percent in Wisconsin. The rate of recipients aged 18-21 per 100,000 state population in that age range averaged 205 but varied across states from 27 to 625. And of the total APTD monthly grants of \$2,817,000 to recipients under 22, nearly half (\$1,233,069) were paid in the State of California. That gross inequity existed prior to the Social Security Amendments of 1972 is unquestionable, although the reason for the differences across states is not readily apparent.

The principal disabling condition, affecting 35.1 percent of the recipient population of all ages, was a mental disorder. No data are available on the client breakdown by handicap for young APTD recipients. As expected, inspection of the APTD breakdown of data by handicap for all ages reveals a high fraction of clients with problems associated with older age, such as heart impairments. Thus, we could not locate reliable data on the handicaps of young needy APTD recipients. Using the incidence rates of handicaps for the U.S. young population, exclusive of those with visual handicaps (since AB rather than APTD serves that clientele), and assuming the expenditures on APTD recipients are approximately the same for each type of handicap, we make the expenditure estimates shown in Table 7.9. Because of the poor quality of the data, these estimates should be interpreted only as approximate order of magnitude figures.

Federal support of the state APTD programs is based on either the formula or alternate method. Table 7.10 shows the financing of the administration, service, and training, and financial assistance portions of APTD for each state. Across the states, the A,S&T expenditures per APTD recipient range from \$53 to \$348, with an average of \$186. Total APTD program expenditures per recipient vary from \$724 to \$1837, with an average of \$1229. A,S&T costs as a proportion of total program cost vary from 5.1 percent to 28.2 percent. Relatively high administrative costs may be a function of many things—low assistance payments, high salaries for caseworkers, or the provision of many services, and therefore cannot be simply attributed to inefficiency.

Principal problems of the pre-1972 APTD program were the variation in definitions of disability and the inequity across states in expenditures per recipient. The new Federal program defines disabled as it is defined for OASDHI. "Permanent" and "total" may still present problems; these will be problems to all states. The new

¹⁸ U.S. Department of Health, Education and Welfare, *Findings of the 1970 APTD Study, Part I. Demographic and Program Characteristics*, Social and Rehabilitation Service, DHEW Publication No. (SRS) 73-03853, September 1972.

Table 7.7

SELECTED CHARACTERISTICS OF STATE AID TO PERMANENTLY AND TOTALLY
DISABLED PROGRAMS, 1970^a

State	Average Monthly Grant ^b	Maximum Monthly Payment	Separate or Combined Program	Property Liens	Allowed Value of House	Personal Property Limit
United States	97					
Alabama	50	79	S	No	2,500	1000
Alaska	177	250	C	Yes	NS ^c	1000
Arizona	79	None	S	No	8,000	400
Arkansas	73	105	C	No	4,500-6,500	500
California	139	128	S	No	NS	1200
Colorado	83	None	S	No	NS	1000
Connecticut	130	None	S	Yes	NS	600
Delaware	125	None	S	No	NS	300
Florida	73	114	C	Yes	NS	600
Georgia	63	91	C	No	NS	800
Hawaii	134	None	C	No	25,000	---
Idaho	80	None	S	No	NS	750
Illinois	91	None	C	Yes	NS	400
Indiana	58	80	S	Yes	NS	350
Iowa	143	None	S	No	NS	500
Kansas	79	None	C	Yes	---	500
Kentucky	76	None	C	No	NS	2000
Louisiana	56	66	S	No	5,000	400
Maine	93	115	C	Yes	NS	500
Maryland	86	None	C	Yes	NS	300
Massachusetts	130	None	S	Yes	NS	1000
Michigan	106	None	S	No	NS	750
Minnesota	92	None	S	Yes	10,000	300
Mississippi	59	75	S	No	2,500	500
Missouri	77	80	S	No	---	---
Montana	89	None	S	Yes	4,999	500
Nebraska	75	None	C	Yes	3,000	750
Nevada	---	---	---	---	---	---
New Hampshire	146	None	S	Yes	1,500	300
New Jersey	107	None	S	Yes	NS	---
New Mexico	75	None	C	No	NS	1200
New York	127	None	C	Yes	NS	NS
North Carolina	77	None	C	Yes	NS	1000
North Dakota	101	None	C	Yes	NS	1000
Ohio	76	None	S	No	NS	300
Oklahoma	97	130	C	No	8,000	350
Oregon	76	None	S	Yes	NS	500
Pennsylvania	101	None	S	Yes	NS	---
Rhode Island	94	None	C	No	NS	1000
South Carolina	56	80	S	No	NS	750
South Dakota	72	None	S	No	NS	1000
Tennessee	68	97	S	No	9,000	500
Texas	67	105	S	No	NS	1800
Utah	73	103	S	Yes	NS	600
Vermont	104	None	C	Yes	NS	900
Virginia	84	None	S	No	NS	400
Washington	97	None	S	No	NS	750
West Virginia	63	None	S	No	NS	1000
Wisconsin	96	None	S	No	NS	750
Wyoming	67	104	S	Yes	3,000	500

^aSource for all information except average monthly grant is U.S. Department of Health, Education and Welfare, *Characteristics of State Public Assistance Plans Under the Social Security Act*, 1970 ed., Social and Rehabilitation Service, Public Assistance Report No. 50, June 1, 1970.

^bU.S. Department of Health, Education and Welfare, *Graphic Presentation of Public Assistance and Related Data, Demographic and Program Characteristics, Financial Characteristics of Recipients, 1971*, Social and Rehabilitation Service, DHEW Publication No. (SRS) 73-03101, October 6, 1972.

^cNot specified.

Table 7.8

AID TO PERMANENTLY AND TOTALLY DISABLED RECIPIENTS, BY AGE, 1970

State	No. of APTD Recipients		Recipients Aged 18-21:		Total Monthly Grants to Aged 18-21 Recipients ^c
	All Ages ^a	Aged 18-21 ^b	As Percent of All Recipients	As Percent of Total Population Aged 18-21	
U.S. total	865,894	29,046	3.4	0.205	2,817,000
Alabama	18,367	654	3.6	0.265	32,700
Alaska	730	7	0.9	0.027	1,239
Arizona	---	---	---	---	---
Arkansas	11,271	338	3.0	0.262	24,674
California	173,948	8,871	5.1	0.627	1,233,069
Colorado	9,562	220	2.3	0.123	18,260
Connecticut	6,916	108	1.6	0.058	14,040
Delaware	1,335	34	2.5	0.091	4,250
Florida	20,836	367	1.8	0.087	26,791
Georgia	33,194	1,175	3.5	0.342	74,025
Hawaii	1,774	58	3.3	0.093	7,772
Idaho	2,739	68	2.5	0.137	5,440
Illinois	41,400	679	1.6	0.093	61,789
Indiana	5,217	196	3.8	0.054	11,360
Iowa	3,078	123	4.0	0.064	17,589
Kansas	5,410	65	1.2	0.038	5,135
Kentucky	16,764	714	4.3	0.296	54,264
Louisiana	21,382	864	4.0	0.316	48,384
Maine	4,233	51	1.2	0.088	4,743
Maryland	15,984	147	0.9	0.056	12,642
Massachusetts	16,686	214	1.3	0.054	27,820
Michigan	26,820	547	2.0	0.089	57,982
Minnesota	11,281	602	5.3	0.229	55,384
Mississippi	21,930	886	4.0	0.533	52,274
Missouri	18,844	716	3.8	0.228	55,132
Montana	2,147	60	2.8	0.127	5,340
Nebraska	4,546	192	4.2	0.182	14,400
Nevada	---	---	---	---	---
New Hampshire	812	4	0.5	0.008	584
New Jersey	12,388	173	1.4	0.041	18,511
New Mexico	8,274	252	3.0	0.347	18,900
New York	76,970	2,802	3.6	0.242	355,854
North Carolina	27,515	534	1.9	0.128	41,118
North Dakota	2,076	40	1.9	0.086	4,040
Ohio	30,823	764	2.5	0.105	58,064
Oklahoma	24,958	559	2.2	0.308	54,223
Oregon	7,536	411	5.5	0.289	31,236
Pennsylvania	43,045	895	2.1	0.118	90,395
Rhode Island	3,983	29	0.7	0.038	2,726
South Carolina	10,435	259	2.5	0.119	14,504
South Dakota	1,482	27	1.8	0.055	1,971
Tennessee	25,110	583	2.3	0.205	39,644
Texas	23,702	1,214	5.1	0.147	81,338
Utah	5,186	335	6.5	0.391	24,455
Vermont	1,878	18	1.0	0.052	1,872
Virginia	7,734	167	2.2	0.046	14,028
Washington	16,352	262	1.6	0.104	25,414
West Virginia	9,397	267	2.8	0.219	16,821
Wisconsin	6,933	455	6.6	0.147	43,680
Wyoming	931	15	1.7	0.067	1,005

^aU.S. Department of Health, Education and Welfare, *Findings of the 1970 APTD Study, Part I. Demographic and Program Characteristics*, Social and Rehabilitation Service, DHEW Publication No. (SRS) 73-03853, September 1972.

^bEstimated by adding the actual number of recipients aged 0-19 plus 2/5 of the actual number of recipients in the 5-year age range of 20-24 years.

^cEstimated by multiplying the number of aged 18-21 recipients by the average monthly grant in the state.

Table 7.9

ESTIMATED 1970 APTD EXPENDITURES ON RECIPIENTS UNDER AGE 22,
BY TYPE OF HANDICAP

Handicap	Expenditures
Hearing impairments	\$ 1,448,000
Speech impairments	12,306,000
Crippling or other health impairments	5,428,000
Mental retardation	9,409,000
Emotional or other nervous disorders	5,066,000
Learning disability	<u>2,533,000</u>
Total	\$36,190,000

program also goes a long way toward equalizing the level of financial assistance in each state.

Since approximately 3.4 percent of APTD recipients are under 22 years old, and assuming the average expenditure per recipient is the same for all ages, we obtain an order of magnitude estimate of a \$36,190,000 total annual expenditure rate for young APTD recipients in 1970. We estimate, on the basis of the United States averages presented in Table 7.10, that the respective Federal, state, and local contributions were \$20,110,000, \$12,750,000, and \$3,330,000.

The President's Commission on Income Maintenance pointed out the relative stability in number of AB recipients versus the rather dramatic increase in APTD recipients.¹⁹ It also pointed out that the blind program has been more generous in terms of the average grant per recipient.²⁰ Indeed this is borne out in Table 7.11, which shows the average grant for AB and APTD recipients in each state. If this is an adequate measure, then it is true that the average AB grant (\$104) is higher than the average APTD grant (\$97). In 33 states the AB grant exceeds the APTD grant; however, the actual dollar difference in average grants is a rather insignificant \$7 per month. Another comparison of programs is via the state-set full standard for each program. The full standard is the amount determined as necessary for basic needs as defined in each state's plan. It is the amount which is compared with income from all sources to determine whether or not financial need exists.²¹ The average monthly full standard for all states is \$150 for AB and \$137 for APTD. Eleven states have a higher full standard for blind than for disabled, while 2 states have a higher APTD standard. In all other states the standards are the same. But even in these other states, AB payments are in general greater than APTD payments (25 states with equal AB and APTD standards have a higher average AB payment). The higher payment to AB recipients might indicate a greater earning ability on the part of APTD recipients, but this cannot be concluded immediately from available information.

A more important observation about Table 7.11 data is that in most cases the

¹⁹ *The President's Commission on Income Maintenance Programs*, p. 268.

²⁰ *Ibid.*, p. 270.

²¹ U.S. Department of Health, Education and Welfare, *Public Assistance Programs: Standards for Basic Needs, July 1971*, Social and Rehabilitation Service, DHEW Publication No. (SRS) 73-03200, March 20, 1972.

Table 7.10
FINANCING OF STATE AID TO THE PERMANENTLY AND TOTALLY DISABLED

State	Number of Recipients, All Ages ^a	Administration, Service & Training Expenditures ^b (A,S&T)				Financial Assistance ^c				Total Expenditures (\$000)				Assistance as Percent of Total APTD Expenditures	A,S&T Expenditures per Recipient	Total Expenditures per Recipient
		Total (\$000)	Federal (%)	State (%)	Local (%)	Total (\$000)	Federal (%)	State (%)	Local (%)	Total	Federal	State	Local			
United States	865,892	161,060	59.5	23.7	16.7	903,399	57.1	35.1	7.8	1,064,459	591,567	375,129	97,763	84.9	\$186	\$1,229
Alabama	18,367	1,653	50.0	48.5	1.5	11,648	77.5	22.5	0.0	13,301	9,851	3,420	30	87.6	90	724
Alaska	730	157	55.9	44.1	---	1,221	35.5	64.4	(d)	1,378	521	856	---	88.6	215	1,888
Arizona	---	406	50.0	47.1	2.9	5,805	74.2	25.8	---	6,211	4,511	1,688	12	93.5	---	---
Arkansas	11,271	600	50.0	50.0	---	11,280	67.2	32.8	---	11,880	7,879	4,001	---	94.9	53	1,054
California ..	173,948	60,486	64.1	7.7	28.2	257,270	48.5	44.1	7.4	317,756	163,671	118,119	35,966	81.0	348	1,827
Colorado	9,562	1,351	66.3	17.1	16.7	7,760	65.8	14.2	20.0	9,111	6,001	1,333	1,777	85.2	141	953
Connecticut ..	6,916	1,553	57.1	42.9	---	9,120	47.4	52.6	---	10,673	5,210	5,463	---	85.4	225	1,543
Delaware	1,335	125	50.0	50.0	---	1,596	48.7	51.3	---	1,721	840	881	---	92.7	94	1,289
Florida	20,836	3,167	63.6	36.4	---	17,718	77.7	22.3	---	20,885	15,786	5,099	---	84.8	152	1,002
Georgia	33,194	2,034	60.2	33.7	6.1	23,452	59.0	34.4	6.6	25,486	15,062	8,755	1,669	92.0	61	768
Hawaii	1,774	318	52.7	47.3	---	2,635	49.0	51.1	---	2,953	1,457	1,496	---	89.2	179	1,665
Idaho	2,739	210	56.7	41.8	1.5	2,599	68.9	31.1	---	2,809	1,910	896	3	92.5	77	1,026
Illinois	41,400	6,439	55.4	44.6	---	45,466	51.2	48.8	---	51,905	26,862	25,043	---	87.6	156	1,254
Indiana	5,217	1,571	60.0	27.4	12.6	8,012	34.9	39.1	26.0	9,583	3,739	3,560	2,284	83.6	301	1,837
Iowa	3,078	430	61.8	36.3	1.9	4,753	55.3	22.4	22.4	5,183	2,893	1,219	1,071	91.7	140	1,684
Kansas	5,410	1,186	59.5	23.9	16.6	6,718	57.7	22.0	20.3	7,904	4,582	1,762	1,560	85.0	219	1,461
Kentucky	16,764	1,110	54.5	45.5	---	13,587	62.6	37.4	---	14,697	9,108	5,588	---	92.4	66	877
Louisiana	21,382	2,630	50.0	50.0	---	14,220	77.4	22.6	---	16,850	12,327	4,522	---	84.4	123	788
Maine	4,233	446	64.5	35.5	---	3,852	62.6	37.4	---	4,298	2,700	1,597	---	89.6	105	1,015
Maryland	15,984	1,960	59.6	32.1	8.3	15,803	59.1	30.7	10.3	17,763	10,501	5,478	1,783	89.0	123	1,111
Massachusetts	16,686	3,846	58.2	41.8	---	21,788	48.7	51.3	---	25,634	12,847	12,787	---	85.0	231	1,536
Michigan	26,820	3,167	50.0	48.8	1.2	28,643	50.0	50.0	---	31,810	15,896	15,875	39	90.0	118	1,186
Minnesota ...	11,281	2,198	64.5	5.2	30.3	10,924	57.0	21.9	21.1	13,122	7,639	2,509	2,975	83.2	195	1,163
Mississippi ...	21,930	1,830	50.0	47.0	3.0	14,582	80.3	19.7	---	16,412	12,629	3,728	54	88.8	83	748
Missouri	13,844	3,006	63.2	36.4	0.4	16,942	66.9	33.1	---	19,948	13,239	6,698	12	84.9	160	1,052
Montana	2,147	398	62.4	12.8	24.7	1,960	65.6	15.4	19.1	2,358	1,533	353	472	83.1	185	1,098
Nebraska	4,546	849	64.0	36.0	---	3,295	---	34.9	---	4,144	2,690	1,455	---	79.5	187	912
Nevada	---	---	---	---	---	---	---	---	---	---	---	---	---	---	---	---
New Hampshire	812	154	66.7	33.3	---	1,031	58.5	6.6	34.9	1,185	706	119	360	87.0	190	1,459
New Jersey ..	12,388	3,275	56.4	3.3	40.3	17,298	42.3	43.3	14.4	20,573	9,162	7,605	3,806	84.1	264	1,561
New Mexico ..	8,274	1,062	61.5	38.5	---	6,724	66.9	33.1	---	7,786	5,151	2,635	---	86.4	128	941
New York	76,970	20,905	56.4	23.0	20.6	98,013	39.0	31.4	29.6	118,918	49,990	35,583	33,345	82.4	272	1,545
N. Carolina ...	27,515	3,197	50.0	21.3	28.7	29,752	69.8	16.7	13.6	32,949	22,352	5,646	4,950	90.3	116	1,197
N. Dakota ...	2,076	476	62.1	14.8	23.1	2,191	70.2	26.7	3.1	2,667	1,832	656	179	82.2	229	1,285
Ohio	30,823	6,798	57.0	39.9	3.1	25,467	66.7	30.5	2.7	32,265	20,873	10,490	902	78.9	221	1,047
Oklahoma	24,958	1,337	50.0	50.0	---	23,418	58.9	41.1	---	24,755	14,451	10,304	---	94.6	54	992
Oregon	7,536	755	50.0	50.0	---	5,653	56.3	43.6	---	6,408	3,563	2,845	---	88.2	100	850
Pennsylvania	43,045	3,344	53.6	46.4	---	32,122	49.5	50.5	---	35,466	17,690	17,776	---	90.6	78	824
Rhode Island	3,983	651	58.0	42.0	---	3,660	49.7	50.3	---	4,311	2,197	2,113	---	84.9	163	1,082
S. Carolina ..	10,435	1,175	50.0	45.3	4.7	6,667	78.0	22.0	---	7,842	5,786	2,001	55	85.0	113	752
S. Dakota ...	1,482	305	53.2	44.1	2.8	1,073	69.9	30.1	---	1,378	912	457	6	77.9	206	930
Tennessee ...	25,110	2,112	55.3	41.7	3.0	19,374	75.0	20.0	5.0	21,486	15,692	4,761	1,033	90.2	84	856
Texas	23,702	2,168	50.0	48.8	1.2	16,711	75.3	24.7	---	18,879	13,665	5,188	26	88.5	91	797
Utah	5,186	832	64.1	35.3	0.6	4,384	60.9	39.1	---	5,216	3,205	2,006	5	84.0	160	1,006
Vermont	1,878	199	63.8	36.2	---	2,081	65.0	35.0	---	2,280	1,479	801	---	91.3	106	1,214
Virginia	7,734	1,658	62.9	2.3	34.8	6,696	65.0	21.8	13.2	8,354	5,395	1,501	1,459	80.2	214	1,085
Washington ...	16,352	1,324	65.8	34.2	---	16,380	48.3	51.7	---	17,704	8,790	8,914	---	92.5	81	1,083
W. Virginia ..	9,397	800	65.7	34.3	---	6,240	75.7	24.3	---	7,040	5,252	1,788	---	88.6	85	749
Wisconsin	6,933	2,131	58.2	21.5	20.3	6,556	54.1	25.5	20.4	8,687	4,788	2,128	1,772	96.9	307	1,253
Wyoming	931	250	63.2	10.6	26.2	635	72.0	14.0	13.9	885	615	116	154	71.8	\$269	\$ 951

^aU.S. Department of Health, Education and Welfare, *Findings of the 1970 APTD Study, Part I. Demographic and Program Characteristics, Social and Rehabilitation Service, DHEW Publication No. (SRS) 73-03853, September 1972.*

^bU.S. Department of Health, Education and Welfare, *Public Assistance: Costs of State and Local Administration, Services and Training, Fiscal Year Ended June 30, 1970, National Center for Social Statistics, NCSS Report F-3 (FY 70).*

^cU.S. Department of Health, Education and Welfare, *Source of Funds Expended for Public Assistance Payments for the Cost of Administration, Services and Training, Fiscal Year Ended June 30, 1970, National Center for Social Statistics, NCSS Report F-2 (FY 70).*

^dBlanks indicate that local agencies supply no money.

Table 7.11

A COMPARISON OF AB AND APTD GRANTS
(\$)

State	Average Annual Per Capita Income of State Population	Average Monthly Grant ^a		Full Standard ^b	
		AB	APTD	AB	APTD
U.S. total	3687	104	97	150 ^c	137 ^c
Alabama	2582	70	50	105	122
Alaska	4460	177	177	250	250
Arizona	3372	81	79	118	118
Arkansas	2488	80	73	109	109
California	4290	160	139	192	172
Colorado	3604	89	83	105	123
Connecticut	4595	101	130	169	169
Delaware	4107	110	125	189	117
Florida	3525	75	73	114	114
Georgia	3071	67	63	105	105
Hawaii	3928	130	134	132	132
Idaho	2953	84	80	163	163
Illinois	4285	93	91	169	169
Indiana	3687	72	58	185	185
Iowa	3549	122	143	161	122
Kansas	3488	79	79	208	208
Kentucky	2847	75	76	96	96
Louisiana	2781	77	56	106	95
Maine	5054	88	93	123	123
Maryland	4073	94	86	130	130
Massachusetts	4156	151	130	180	178
Michigan	3994	106	106	224	224
Minnesota	3635	101	92	183	183
Mississippi	2218	59	59	150	150
Missouri	3458	91	77	250	170
Montana	3130	94	89	120	120
Nebraska	3609	93	75	182	182
Nevada	4458	92	---	155	---
New Hampshire	3471	169	146	173	173
New Jersey	4241	100	107	142	142
New Mexico	2897	78	75	116	116
New York	4442	136	127	159	159
North Carolina	2888	85	77	120	112
North Dakota	3012	104	101	125	125
Ohio	3738	75	76	126	126
Oklahoma	3047	106	97	130	130
Oregon	3573	104	76	163	153
Pennsylvania	3659	121	101	150	146
Rhode Island	3858	85	94	163	163
South Carolina	2607	67	56	103	87
South Dakota	3027	96	72	180	180
Tennessee	2808	70	68	102	102
Texas	3259	79	67	116	116
Utah	2997	87	73	151	151
Vermont	3247	102	104	177	177
Virginia	3307	86	84	153	152
Washington	3848	98	97	143	143
West Virginia	2603	69	63	146	146
Wisconsin	3632	91	96	158	158
Wyoming	3353	---	67	139	127

^aU.S. Department of Health, Education and Welfare, *Graphic Presentation of Public Assistance and Related Data, Demographic and Program Characteristics, Financial Characteristics of Recipients, 1971*, Social and Rehabilitation Service, DHEW Publication No. (SRS) 73-03101, October 6, 1972.

^bU.S. Department of Health, Education and Welfare, *Public Assistance Programs: Standards for Basic Needs, July 1971*, Social and Rehabilitation Service, DHEW Publication No. (SRS) 72-03200, March 20, 1972.

^cAverage of 50 states' full standards.

current average payment for either AB or APTD is far below full standard levels, and is a rather small amount of financial assistance. Under the new program the minimum payment will be \$130. For 17 states this exceeds the current full standard for both AB and APTD programs. For 3 states it exceeds the APTD but not the AB standard. In addition, the new minimum payment of \$130 is generally more than the current state average grant. Only 5 states currently average \$130 in both programs; one averages more in its AB program and two average more in APTD programs. The new program will therefore dramatically affect the income level of current AB and APTD recipients, although the question remains: Is this new income level adequate?

Aid to Families with Dependent Children. As stated earlier, AFDC is basically an income maintenance program, which is not intended to service handicapped youth specifically, but rather families with children to whom assistance payments are given based on the family's need.

While several studies have been made of AFDC, only one investigated the incidence of mental or physical impairment among AFDC children. In the AFDC study of 1967, published in 1970, mental and physical impairments are reported for 47 percent of the estimated 3.9 million recipient children in late 1967.²² For each impairment a "professional" and "other" opinion are listed. Adding these two opinions together gives the total for each major impairment, as shown in Table 7.12.

Table 7.12
IMPAIRMENTS AMONG AFDC RECIPIENT YOUTH

Handicap	Percent with Impairment		
	Total	Professional Opinion	Other Opinion
Visual defects	7.7	4.9	2.8
Hearing impairments	2.7	1.7	1.0
Speech defects	3.2	1.8	1.4
Orthopedic impairments	3.4	2.2	1.2
Mental retardation	3.9	2.3	1.6
Emotional or other nervous disorders	5.8	2.6	3.2
Heart abnormality	2.4	1.6	0.8
Other chronic impairments	6.4	3.3	3.1
Dental impairments	11.5	4.9	6.6
Total	47.0	25.3	21.7

These figures indicate that approximately 25 percent of AFDC recipient youth have some physical or mental impairment as evaluated by a professional, and an additional 22 percent are cited by nonprofessionals as being impaired. The data are not of high utility to our study because the 1967 survey team did not give a medical exam to each youth in the study, and because the data include youth with slight

²² U.S. Department of Health, Education and Welfare, *Findings of the 1967 AFDC Study, Part I. Demographic and Program Characteristics*, National Center for Social Statistics, NCSS Report AFDC-3 (67), July 1970.

impairments, e.g., the category "visual impairments" is large, loosely defined, and certainly includes more than legally blind youth. In contrast to the 25.3 percent reported by professional opinion as mentally or physically impaired in the 1967 AFDC survey, the percentage of the total population of youth with an impairment of sufficient magnitude to be termed a handicap is only about half that large (see Appendix A for a description of the handicapped youth population).

One striking example of the definitional differences between the AFDC survey and our research occurs with respect to visual impairment; while the AFDC survey reports that 4.9 percent have "some visual defect," the number of youth in the total population with a visual "handicap" from the viewpoint of our research is estimated to be only 0.2 percent. If we were to ignore these definitional differences, major inconsistencies would result, e.g., there are more youth with some visual defect receiving AFDC than there are visually handicapped youth in the entire U.S. population. Consequently, we have chosen not to use the 1967 AFDC survey data in estimating the number of handicapped youth served by AFDC.

Without better data, we assume that the incidence rate of handicapping conditions in AFDC recipient youth is the same as the incidence rate for the entire U.S. young population.

In March 1971,²³ there were 7,371,000 child recipients of AFDC in the United States, and the average monthly payment per recipient was \$49.60. In FY 1970 the respective Federal, state, and local contributions were 53.6, 35.3, and 11.1 percent of the total. Assuming that the average grant for handicapped youth is the same as that for all AFDC recipients, then we estimate a total of 975,920 handicapped youth received AFDC in March 1971, at a total annual assistance expenditure level of \$580,868,000. Of the total, approximately \$311,345,000 were Federal funds, \$205,046,000 were state funds, and \$64,476,000 were local funds.

General Assistance

The third aspect of income maintenance in the United States is General Assistance. This is a noncategorical program that provides financial assistance on the basis of need. The programs are financed solely from state and local tax revenues; there is no Federal contribution. Consequently, each state is left entirely on its own to decide if there should be a GA program, what purposes it should serve, the eligibility standards, benefit levels, and administrative agencies and procedures.

It is difficult to generalize about the GA programs because of the wide range of differences among the states. *Characteristics of General Assistance in the U.S.*,²⁴ shows that in many states GA is limited to short-term and emergency assistance only. Many states make assistance dependent upon a work test, limiting assistance to unemployable persons or to families without an employable member. None of the requirements relate specifically to a handicap condition; presumably this would be accounted for where a work test is used. In addition, more than half of the states have relatives' financial responsibility laws. In 17 states, GA is financed completely

²³ U.S. Department of Health, Education and Welfare, *AFDC: Selected Statistical Data on Families Aided and Program Operations*, National Center for Social Statistics Report, NCSS Report H-4(71), June 1971.

²⁴ U.S. Department of Health, Education and Welfare, *Characteristics of General Assistance in the U.S.*, 1970 ed., Social and Rehabilitation Service, Public Assistance Report No. 39, December 31, 1969.

by the local jurisdiction. The number of GA recipients in 1970 was 1,056,000, and the average monthly grant per recipient was \$58.²⁵

Details are shown in Table 7.13. Unfortunately, the data do not relate at all to handicap as the information is neither kept nor reported on that basis; however, we suspect very few handicapped youth receive GA on a long-term basis because of the incentive for states to place such youth on the AB, APTD, or AFDC programs where Federal funding can be obtained. Some states may place the youth on this type of assistance temporarily while they are evaluated for eligibility to receive one of the federally supported types of assistance.

Income Tax Exemptions for the Handicapped

Legally blind persons are the only handicapped allowed to claim an additional exemption on Federal income taxes. The exemption may be claimed for a taxpayer or for his spouse but not for other dependents; thus, an extra exemption for handicapped youth cannot be claimed on the parents' tax return. In 1970, the latest year for which data are available, a total of 126,171 such exemptions were claimed for blindness.²⁶ At a marginal tax rate of 20 percent,²⁷ the \$600 exemption means a tax reduction of \$120 per person or about \$15,000,000 for all persons claiming the exemption. Since Internal Revenue Service data are not disaggregated by age of taxpayer, the number of youth under age 22 claiming the exemption can only be estimated. If we assume that no more than half of the legally blind persons aged 17-21 would be able to claim the extra exemption, then the total income tax reduction for blind youth would be on the order of \$1,000,000 a year.

OTHER SOCIAL WELFARE AGENCY SERVICES

Income maintenance is only one of many services State Welfare Departments offer. Other services offered depend upon the state's governmental organization—whether public welfare is a separate department or an agency within another department. In Nebraska, for example, where public welfare is a department by itself, major programs are as follows: services to crippled children; medical assistance (Title XIX); AFDC; Aid to the Aged, Blind, and Disabled; Nebraska Center for Children and Youth; and social services. In contrast, public assistance in New Mexico is administered by the Public Assistance Agency, a subgroup in the Department of Health and Social Services. Their concern is programs only for people receiving financial assistance—AFDC, AB, APTD, medical assistance, and food assistance.

Of the above programs, those dealing with income maintenance are discussed in this section. Programs for crippled children and medical assistance are discussed

²⁵ U.S. Department of Health, Education and Welfare, *Graphic Presentation of Public Assistance and Related Data, Demographic and Program Characteristics, Financial Characteristics of Recipients, 1971*, Social and Rehabilitation Service, DHEW Publication No. (SRS) 73-03101, October 6, 1972, pp. 3, 30.

²⁶ Internal Revenue Service, *Statistics on Income—Individual Income Tax Returns*, Publication 198, 1970.

²⁷ The 1972 marginal tax rate on a married person filing jointly with a taxable income of \$4000 to \$8000 was 19 percent, while the comparable rate for a single person earning \$4000 to \$6000 was 21 percent.

Table 7.13
GENERAL ASSISTANCE IN JUNE 1972

State	Average Grant (\$)	Number of Recipients
United States	67	548,000
Alabama	13	140
Alaska	38	412
Arizona	35	6,627
Arkansas	6	816
California	77	54,740
Colorado	87	4,213
Connecticut	49	20,766
Delaware	30	5,025
Florida ^a	---	20,700
Georgia	25	2,979
Hawaii	67	15,505
Idaho ^b	---	---
Illinois	84	55,322
Indiana	---	---
Iowa ^a	---	8,300
Kansas	65	9,003
Kentucky ^b	---	---
Louisiana	51	9,077
Maine	18	11,432
Maryland	87	15,511
Massachusetts	69	41,532
Michigan	81	67,402
Minnesota	53	14,763
Mississippi	15	1,398
Missouri	62	14,789
Montana	22	1,731
Nebraska ^b	---	---
Nevada ^b	---	---
New Hampshire	31	2,766
New Jersey	134	13,285
New Mexico ^b	---	---
New York	68	230,333
North Carolina	15	3,220
North Dakota	17	642
Ohio	51	77,250
Oklahoma	9	3,541
Oregon	53	2,862
Pennsylvania	97	112,254
Rhode Island	40	13,360
South Carolina	32	326
South Dakota	15	901
Tennessee	13	4,094
Texas ^b	---	---
Utah	64	1,303
Vermont ^b	---	---
Virginia	65	9,622
Washington	71	4,710
West Virginia	11	2,950
Wisconsin ^a	59	14,518
Wyoming	23	301

SOURCE: U.S. Department of Health, Education and Welfare, *Public Assistance Statistics, June 1972, October 3, 1972.*

^a Estimated.

^b Not available.

in Sec. 8. Social service programs as related to public welfare, with the exception of vocational rehabilitation services for welfare recipients discussed in Sec. 5, cannot be discussed in detail because data and information are lacking. In addition, it is difficult to describe what constitutes social service because of great variation from state to state.

One state's annual report, for example, says that "... The Division of Social Services is responsible for the provision of services to all appropriate members of AFDC..." Under the heading of services offered to adults receiving assistance, the description is only slightly more specific—protective services, services to meet health needs, self-support services for the handicapped, services to aged in and leaving mental hospitals, and services to enable persons to remain in or return to their own homes or communities. Another state talks of services to children and their families; these include foster care, adoptions, licensing of child care institutions and day care staff, protective services, homemaker services, and family planning and services to unmarried parents. Others mention specific services for the blind such as home teaching and/or special libraries, rehabilitation, register of the blind, sight conservation program, and workshops.

With such a range of services spread across different agencies and the almost total lack of social service data, it is not feasible to adequately describe the miscellaneous "social services" available to handicapped youth. The one measure of the extent of these services is shown in Tables 7.6 and 7.10, in which AB and APTD program totals are divided into funds for financial assistance versus A,S&T. The data problems are best summarized by some of the responses received as a result of our state agency survey. With respect to social services, one reply stated that "... several programs are operated ... in behalf of individuals under 21 years of age. However, these programs are not limited to the handicapped and, therefore, data specifically related to the handicapped are not available." Another state responded quite candidly by saying "... we have concluded that we really have very little statistical data related to handicapped youth..."

SURVEY RESPONSES FROM STATE PUBLIC WELFARE AGENCIES

As part of this study effort, we conducted a survey of all agencies serving handicapped youth. Public welfare was one of the agencies queried. The purpose of the survey is explained in Appendix B, and a copy of the questionnaire used appears in Appendix D.

Survey responses from public welfare agencies in general were poor, primarily for reasons noted earlier; in particular, they were poor because public welfare programs "do not seek to serve handicapped youth *per se*..." and thus do not have data specific to that target population. Many states did send copies of annual reports, special reports, and enabling legislation. From the standpoint of data, these provided very little. They were in general a presentation, by county, of data reported federally. For an AB program, for example, they might give numbers served and average grant per recipient in each county. Only a few states were able to estimate the number of handicapped youth served in the AB or APTD programs. The welfare agencies in general, however, were very cooperative and provided whatever infor-

mation they had available. While little solid data related to handicapped youth were forthcoming, the large volume of program descriptive information will be valuable in explaining differences across states and in formulating recommendations for program improvement to appear in subsequent reports on this research project.

One of the best responses came from North Dakota. Its AFDC program served 9802 persons 21 years of age or under in FY 1972. Of these, 35 percent (3435) were handicapped. The percentage breakdown by type of handicap was reported as follows:

Emotional or other disorders	7.0
Speech defects	4.8
Mental retardation	4.7
Orthopedic impairment	4.6
Hearing impairment	3.6
Heart abnormality or rheumatic fever	2.8
Other chronic condition	7.5

The average AFDC monthly payment per child for maintenance income was \$58.74. AB, however, had only 4 cases under 21 years of age, and they received an average monthly assistance payment of \$109.38. The Aid to the Disabled program served 25 people aged 21 or under in 1972. Five of these were emotionally or mentally disturbed, 8 were mentally retarded, 7 had cerebral palsy, and 5 were classified as other.

The social service program served an average of 1278 persons per month under the age of 21. The cost of services to this group was 35 percent of the total social service program. One of the only programs offered in any state that is directed specifically to youth is the Early Periodic Screening, Diagnosis and Treatment of Individuals under age 21. This program provides preventive health services and early detection and treatment of disease in children eligible for medical assistance. The program also provides for supplying eye glasses, hearing aids, and dental care. More detailed discussion of this type of program is contained in Sec. 8 dealing with health care.

New Mexico furnished another estimate of youth served. It estimated that 8 percent of those helped in their AB program are 21 or under, while only 3 percent of the APTD recipients are in this age group.

Prompted by problems created by increasing caseloads, the California Department of Welfare undertook a study of the primary impairment of APTD recipients by age. For the group aged 18-29, their findings, shown in Table 7.14,²⁸ indicate that 64 percent of the APTD recipients were either mentally or emotionally disturbed. Another 13 percent had a disease of the nervous system or sense organs. Unfortunately, these figures cannot be compared with data reported from other states because of the difference in age categories.

Another state reported data for children receiving foster care. Of 3500 children in its program, it estimated that 13 percent are physically handicapped, 10 percent are mentally retarded, and 18 percent have either a diagnosed or suspected emotional disturbance. Unfortunately, the percentage figures are not current but are based on a 1961 state study of children in foster care.

²⁸ Figures based on findings from a California 3 percent sample of recipients in November 1967.

Table 7.14

AID TO THE DISABLED IN CALIFORNIA, NOVEMBER 1967
(Primary impairment of recipients aged 18-29 in
descending rank order by impairment group)

Primary Impairment	Number	Percent
Mental deficiency	7,189	47.5
Mental, psychoneurotic, and personality disorders	2,410	15.8
Diseases of the nervous system and sense organs	1,995	13.1
Accidents, poisoning, and violence	904	5.9
Diseases of the bones and organs of movement	640	4.2
Congenital malformations	452	3.0
Diseases of the circulatory system	377	2.5
Infective and parasitic diseases	339	2.2
Diseases of the blood and blood-forming organs	226	1.5
Neoplasms	151	1.0
Symptoms, senility, and ill-defined conditions	151	1.0
Allergic, endocrine system, metabolic and nutritional disease	113	0.7
Diseases of the genito-urinary system	38	0.2
Diseases of the skin and cellular tissue	38	0.2
Unspecified	188	1.2
Total recipients aged 18-29	15,211	100.0

Responses from our survey of state public welfare agencies included reports on program problems: inadequate financial support for the program, poor coordination of services, difficulties in joint state-county administration of the program, too low a Federal ceiling on social services, and transportation problems of the handicapped.

PREVIOUS STUDIES AND DATA AVAILABILITY

There are no major studies that specifically investigated income maintenance and handicapped youth. Whenever the subject of the handicapped was addressed, it was as part of a larger study, such as characteristics of AB or APTD recipients. Income maintenance studies have similarly not looked at this group in detail. Even though not addressed to handicapped youth, some studies are worth reviewing here because of either general information on the handicapped population or income maintenance programs. We examine two studies of income maintenance and welfare, a series of studies published by the National Center for Social Statistics on AB, APTD, and AFDC, and two general population surveys.

Income and Welfare in the United States investigated the causes of poverty and dependency.²⁹ As the authors state in the preface, their intent is to explain the

²⁹ J. N. Morgan et al., *Income and Welfare in the United States*, McGraw-Hill, New York, 1962.

details of income, not just the shape of the income distribution curve. In addition to economic data, the study tried to capture what influence various psychological and sociological variables have on income. Having derived a model of income determination, they use this to examine two groups, the poor and the disabled.

Data are presented for interviews with 860 disabled adults, in which the basis for considering the individual as disabled was the respondent's perception of his condition as it affects his ability to work. One conclusion was that the extent of work limitation was relatively independent of demographic characteristics and individual attitudes. One estimate of income loss due to disability was \$14 billion. With respect to outlook of the disabled, this study concluded that rehabilitation services currently available would benefit only a few of the disabled and that the rest would either have to rehabilitate themselves or continue as they are.

Of the group interviewed in this study, only 4 percent were under 25. Even though the study does not consider handicapped youth as a group, it is worth noting for its methodology in attempts to estimate the impacts of transfer payments with respect to decreasing dependency and for the consideration of social and psychological factors as they affect the work potential of the disabled.

The President's Commission on Income Maintenance Programs was convened in 1968 to evaluate existing and proposed income maintenance programs and to recommend a new and better program. The three-part report describes the characteristics of income maintenance recipients, the existing programs, and proposed new programs. The report is useful for a number of reasons. First, it presents criteria for evaluating transfer programs. Then it discusses the philosophy and workings of existing programs, pointing out where these fall short of the criteria established. The discussions of income maintenance programs for the handicapped are brief, intended to be descriptive not critical. Problem areas are noted for programs, e.g., for the APTD program they cite inequity in the definition of disability and inadequacy of income for the eligible. It is unfortunate that the treatment of the two handicapped programs is so slight, for while the discussions of welfare are not necessarily new, they are direct and insightful and addressed directly to the total program of income maintenance in the United States.

National Center for Social Statistics, Various Reports on AFDC, AB, and APTD. Special surveys of AB and APTD recipients were conducted in 1962 and 1970; studies of AFDC recipients were made in 1961, 1967, 1969, and 1971. Each study presents the best data available on demographic and program characteristics as well as a second part describing the financial circumstances of recipients. All of the findings are based on a representative sample of cases. Since all AB and APTD programs have a minimum age requirement of 16 and 18, respectively, study results pertain to only a small portion of the population of interest to this study.

The 1962 AB and APTD reports are somewhat more useful than the 1970 reports because they contain more detailed medical and health data. For example, the 1962 AB study presents a cross-tabulation of etiology of blindness by race; the 1970 study has no etiology data. In addition, the 1962 AB study has a cross-tabulation, by race, of age at loss of sight. Again the 1970 study presents no like data. A similar problem exists with the AFDC studies—the older one has more interesting data; i.e., the 1967 study presents information on selected physical and mental impairments of AFDC children, the 1971 study does not.

In general, future versions of these studies, if properly designed, could be excellent data sources on handicapped youth served by public welfare programs. The National Center for Social Statistics is to be commended for conducting these sample surveys as an excellent means of obtaining needed program evaluation data. The present state of data on welfare programs, however, does not allow one to look in detail at the handicapped youth subsets of the total recipient caseload.

Social Security Survey of the Disabled, 1966. Funded by the Social Security Administration, this study was a national survey of disability in the general adult population. The survey objectives were (1) to describe the prevalence and work limiting effects of disability, (2) to examine the effects of disability on income and rehabilitation, (3) to investigate the overlap of public assistance programs and OASDHI recipients, and (4) to examine new work experience requirements for OASDHI eligibility. The survey population included all disabled adults aged 18-64, both institutionalized and noninstitutionalized. The definition of disability used was a limitation on the kind or amount of work (including housework) resulting from a chronic health condition or impairment lasting three or more months. Although different from the APTD definition of disability, the study results are important because they point out the overlap in AB and APTD recipients with OASDHI recipients. Of 2,505,000 OASDHI recipients, 188,000 were found to also be receiving public assistance payments; however, few of the public assistance recipients, including those who were disabled, had the required work experience under Social Security to be insured for disability. That is, the study found that 24 percent of the disabled public assistance recipients had been disabled in childhood and hence would have no disability insurance because they lacked work experience. These data suggest that OASDHI and public assistance programs serve two basically different populations.

Social and Rehabilitation Services Survey, 1972. This very detailed and comprehensive survey has two components: a survey of the adult general population, and a survey of welfare and rehabilitation clients. Results will not be available until late 1973.

8. FEDERAL AND STATE HEALTH PROGRAMS FOR HANDICAPPED YOUTH

This section summarizes health programs relating to handicapped youth, and then discusses the Federal role in these programs. Next, two of the more significant service programs dealing with the specific needs of the handicapped are discussed: the Maternal and Child Health Service (MCHS) and the Crippled Children's Service (CCS). Then several other public health programs are described which provide services to handicapped as well as to all children in general. Finally, responses to our state survey of health agencies are presented, and available data and previous research in this area are reviewed.

OVERVIEW AND SUMMARY

Children are entitled to good health care, and handicapped children are no different from normal ones in this regard, except that they need more services and resources. The total contribution to "good health" that accrues to all children, including the handicapped, comes from a wide assortment of publicly and privately provided health services.

Federally supported programs providing health services are estimated to have assisted at least one million handicapped youth in FY 1971. A total of over one and one-half million children were reported to have been served by the different health programs, but some unknown amount of double-counting is included because of youth receiving service from more than one program. Total Federal and state expenditures in this area were at least \$314 million in FY 1971, of which the Federal share was \$205 million and the state share was \$109 million. State and local expenditures not known or reported to the Federal Government would raise the total even further. The breakdown of these figures, shown in Tables 8.1 and 8.2, indicates that the largest single program in this area is Medicaid, which serves youth from financially needy families. The second largest is the Crippled Children's Service which is designed to serve children having nearly *all* types of handicapping conditions. Table 8.3 shows the funds expended by type of handicap, based on data of questionable reliability.

The medical services can be considered as a delivery system, represented by a mix of models, functions, rationales and processes that cannot be adequately de-

Table 8.1

ESTIMATED FEDERAL AND STATE HEALTH PROGRAM EXPENDITURES
FOR HANDICAPPED YOUTH, 1971

Program	Expenditures		
	Federal	State	Total
Crippled Children's Service	\$ 58,598,000	\$ 27,299,000 ^a	\$ 87,897,000
Other Maternal and Child Health Programs	25,000,000	(b)	25,000,000
Medicaid	105,548,000	80,255,000	185,803,000
Community Health Care--rubella immunization	16,000,000 ^c	(b)	16,000,000
Other State and Federal Public Health Programs ^d	(b)	(b)	(b)
Total	\$205,146,000	\$109,554,000	\$314,700,000

SOURCE: See later portions of this section for data sources and estimation methods.

^a Amount required to match Federal CCS funds only. The actual total state and local contribution may be as much as twice the amount shown.

^b Not estimated.

^c FY 1970.

^d For a description of these programs, not primarily intended to serve handicapped youth, see the subsection entitled "Other Public Health Programs" in this section.

Table 8.2

ESTIMATED NUMBER OF HANDICAPPED YOUTH RECEIVING
HEALTH SERVICES, 1971

Program	Number of Handicapped Youth
Crippled Children's Service	485,000
Other Maternal and Child Health Programs	81,000 ^a
Medicaid	1,097,000
Community Health Care--rubella immunization	(b)
Other State and Federal Public Health Programs	(b)

SOURCE: See later portions of this section for data sources and estimation methods.

^a Note that this is an estimate of *handicapped* youth served, not *total* served, and hence may appear at first glance to be undersized.

^b Not estimated.

Table 8.3

ESTIMATED FEDERAL AND STATE EXPENDITURES FOR HEALTH SERVICES
TO YOUTH BY TYPE OF HANDICAP, 1971

Type of Handicap	Estimated Expenditures
Visual impairment	\$ 28,663,000
Hearing impairment	28,415,000
Speech impairment	61,315,000
Crippling and other health impairments	101,001,000
Mental retardation	54,354,000
Emotional or other nervous disorders	27,946,000
Learning disability	13,006,000
Total	\$314,700,000

SOURCE: See later portions of this section for data sources and estimation methods.

scribed collectively. Medicaid, for instance, is a reasonably good example of the Controllership model, functioning primarily through Federal control of all but the delegated provision of services (which the states and localities do) and rationalized as a program that provides needed redistribution of resources and basic support for services that would otherwise not be provided. The Maternal and Child Health Services, including Crippled Children's Services, are by comparison best described as species of the Special Revenue Sharing Model; but even here there are some subtle but important differences.

CCS programs concentrate heavily on medical treatment, are operated by doctors, and stress quality medical care for a range of handicaps that encompasses the "simplest" clubfoot to extraordinarily exotic disorders. MCHS programs, however, encompass a bewildering variety of some 200 distinct services and activities, which are not consistently provided in all states and localities, and stress identification through screening and registration mechanisms and prevention via immunization and other disease specific programs.

A distinction between CCS and MCHS is summarized in terms of our concept of the Plus in the Special Revenue Sharing, Plus model. In this case, the Plus is not exercised by Federal officials in either MCHS or CCS, although they have the rudiments of an information system with which it could be in CCS. Quality control is built into the CCS program through professional, historical, and structural guides that may or may not be reproducible for other related health service programs. The MCHS and CCS programs are grant providing mechanisms, rationalized primarily according to redistribution of resources arguments and secondarily by basic service support.

Crippled Children's Services

As of 1972, Crippled Children's Service programs were reaching some 491,000 children aged 0-21, and 29.5 percent of those served were aged 4 or less. CCS provides medical services to youth in financially needy families, although the determination of financial need is left to state officials. Males have traditionally outnumbered

females over the years, and in 1970 the breakdown by sex of the total caseload was 54.5 percent male and 45.5 percent female. Racial characteristics are recorded only to the extent of listing whether the recipient is "white," "all other," or "not reported," and this breakdown was respectively, 66.8 percent, 24.0 percent, and 9.2 percent.

The bulk of the services provided were for physician visits and medical treatment; however, some 82,000 were served as hospital inpatients. About 90,000 were listed as multiple handicap recipients. Three general classes of impairment account for 69.8 percent of the total CCS caseload: impairment of the bones and organs of movement (25.2 percent), diseases of the nervous system and sense organs (24.2 percent), and congenital malformations (20.4 percent). The word "crippled" in the program title is presently a misnomer, since the program serves youth with virtually all types of medical problems.

Large variations exist on a state-by-state comparative basis, as compared with national averages of impairment covered, the extent of multiple handicapping reported, and the amounts of resources expended per recipient. For example, as contrasted with the national percentage breakdowns for the top three disease classes, Wisconsin reported 39.6 percent of its caseload was concerned with diseases of the nervous system and sense organs, but Kansas had only 8.3 percent; for diseases of the bones and organs of movement, Vermont reported 52.1 percent of its caseload in this category, while Oklahoma had only 6.6 percent; and for congenital malformations, Connecticut reported 39.8 percent of its caseload devoted to this disease class, and Oklahoma had only 5.2 percent. With respect to the reporting of multiple handicaps, Minnesota lead all other states with 53.5 percent of its total caseload reported as multiply handicapped (compared with a national average of 18.5 percent) but, on the other end of the scale, Rhode Island reported only 2.6 percent similarly handicapped. When considering per client Federal expenditures on a state-by-state basis, the discrepancies are quite pronounced. These figures range from a low in Washington, D.C., of \$26.90 to a high of \$249.17 in Ohio, as contrasted with a national average Federal per client value of \$117.76.

Program highlights and distinguishing features of the CCS program include the following: high standards are maintained by the liberal use and control of the program by medical specialists; local needs are reflected in marginal variations in coverage that exist from state to state (this does not explain the wider variations that have been noted, however); the medical community has generally accepted CCS as "one of its own" programs as distinguished from Title XIX and welfare related health programs; and operational data are routinely and comprehensively collected according to a common format from all states to enable programmatic analyses.

CCS is reaching only a fraction of those who might benefit from it. Categorical coverage, as determined locally according to available resources and local preferences for certain classes of impairments over others, contributes to inequitable coverage from state to state and within the same state at different phases of the fiscal year. Planning and resource guidance information, and indeed coordination of related health centered services for handicapped children, do not exist to any noticeable extent. Nonetheless, the CCS model is a durable, time-tested one that has some general applicability—from all indications we received in interviews, from the survey questionnaire, and from our review of the few analyses made of it.

Maternal and Child Health Services

Other programs sponsored by Maternal and Child Health Services are widely diverse and rather difficult to appraise. Doubtless underlying many program initiatives is the need to be both comprehensive and humanitarian; however, the actual results obtained are difficult to assess or trade off with other competitive services because of vague objectives, inadequate resources, poor coordination, and lack of accountability data.

In FY 1972, the MCHS budget, exclusive of CCS funds, was \$177 million to improve and expand medical services related to maternal and child health, but the portion accruing to handicapped children is not clearly indicated.

One must take great care to separate each of the MCHS programs in making any summary assessments of the total activity. For instance, some 56 facilities to support the Maternal and Infant Care (M&I) program were funded in FY 1973 at a cost of some \$46.332 million; Intensive Care of Infants was supported at a rate of \$900,000 in some eight separate facilities; and programs for Children and Youth (C&Y) were conducted in 59 facilities at a cost of \$52.842 million in the same period. Each program is intended to accomplish different objectives, and each must be carefully appraised by matching its objectives against its accomplishments. The M&I and C&Y programs were aimed specifically, for example, at urban slum areas and brought medical treatment services to thousands of mothers and children who otherwise would not have benefited. In the most general sense, these programs have had some preventive impact on the total handicapped population, reducing to some extent the number of children who otherwise might have later been "handicapped." However there are problems in accounting for these programs in the context of an analysis of *services to the handicapped*.

These programs include a variety of activities and services related to the health of handicapped and nonhandicapped preschool and school-aged children (e.g., vision and hearing screening; and rubella immunization campaigns). During FY 1972, over 300,000 mothers received maternity nursing services, but who could say how many of these women actually bore handicapped offspring, or more difficult yet, how many handicapped children were prevented as a result of these nursing visits? Mental retardation clinics served 57,000 children, but over 2 million youth in the United States are retarded. PKU screening was given to 9 of 10 live births in FY 1972, some number of PKU children were detected, and remedial treatments were begun. Although data are not available, these programs undoubtedly had many beneficial impacts, although how far reaching is unknown. It may be because a carefully documented case for their effectiveness is not easily made, among a host of other explicit reasons, that they are presently the target of much Federal interest as possible candidates for special revenue sharing.

Medicaid

Medicaid reached some 8.3 million youth aged 0-21 with medical services in FY 1971 at a total dollar cost of \$5.939 billion. Eligibility for these funds and services is determined according to the family's financial need in addition to the child's medical needs. Available data do not show how many of what kinds and degrees of handicaps are truly represented in these totals. To arrive at wholly reliable data on

the handicapped youth served by Medicaid would require a case-by-case investigation and reconstruction and, even at that, there would still be problems because of the ways certain types of handicaps have been noted for the record; e.g., in some states, social workers, not mental retardation specialists, determine whether or not a youth is mentally retarded. Without better data, we utilized data on the proportion of the U.S. population under age 22 that is handicapped to make order of magnitude estimates of the handicapped served by Medicaid. We estimate that some one million children were both Medicaid recipients and handicapped in FY 1971; in dollar terms, this amounts to \$105 million for the Federal share, and \$186 million total, including the state shares. One noteworthy feature of this program is the provision for mandatory, early, and periodic screening, diagnosis, and treatment of all Medicaid-eligible children.

Other Public Health Services

There are other public health related services supported with Federal resources that relate to children generally and therefore have some hard-to-estimate impact on handicapped children as well. We summarize several formula and grant programs designed to provide comprehensive and improved local health care; e.g., "Hill-Burton" construction programs, health services development projects, dental care and screening, and several community service activities. Because the objectives of some of these programs are, to varying degrees, vague and rationalized in humanitarian terms, it is difficult to assess to what degree certain of these individual programs have accomplished their objectives. Examples of Veterans Administration, Defense, and other efforts that relate to health services for handicapped children are noted, not because the number of children or size of resources expended are large, but because the existence of these programs illustrates how fragmented health services to handicapped children are.

The fragmentation and coordination issues were underscored in the questionnaire survey responses as well. Problems noted in the survey responses included concern that the level of funding has grown much more slowly than the rate of inflation of medical service costs, that coordination at the delivery level is not always well or easily accomplished, and that it is difficult to determine who should receive services. Where legitimate demand exceeds resource capacities, some thorny ethical problems of choice have emerged; e.g., should a state decide to serve many children having relatively inexpensive disorders, or should it concentrate its resources on a smaller number of children suffering from more exotic and expensive ones?

Basic Observations

Our basic observations about Federal and State Health Programs for Handicapped Children follow:

- The provision of services is fragmented in this system, composed as it is of a melange of organized public, quasi-public, voluntary, and private agencies. There is little effective organized cooperation at the Federal level: there is at best haphazard orchestration of services at the local and state level, and there is no

systematic means by which relative service priorities and performance are being assessed.

- A natural outcome of the existing system structure is the absence of widely-known, locally-accessible referral services. Consequently, clients are faced with such a labyrinth of subsystems and related services that securing the appropriate mix of needed assistance is extremely difficult.
- Evaluation and monitoring of program performance are not systematically or routinely done, and any coherent data base for these purposes is notable (with only minor exceptions) mostly by its absence.
- *Inequity* of service exists as measured and estimated along a variety of dimensions. However, *inadequacy* of service provision does *not* appear to be as great a problem as in other service areas. The rich have excellent medical services if they are willing to search them out and pay for them; and the poor, due mainly to the Medicaid and crippled children's programs, do have an institutional mechanism to which they can appeal for medical assistance for their handicapped children. The mere existence of services says nothing, however, about differences in the quality of those services.
- Most medical programs are *not* aimed primarily at handicapped children, but are distinctly oriented to provide general health services.

ROLES AND GOALS

There is a striking contrast between MCHS and CCS program operations when considered from the perspective of our four Federal institutional models. Superficially, both appear in practice to be examples of Model III, Special Revenue Sharing; however, the big difference is the Plus factor. To oversimplify somewhat, MCHS, particularly the formula grant portion of it, is operating without much of the evaluation and control Plus, but CCS programs have partially structured the Plus factor into their operations in a number of interesting ways. For CCS the decisive factor includes strong elements of professional medical control; i.e., the insertion of professional norms and incentives by virtue of the proportion of doctors who actually operate CCS programs, the requirement for board certification of specialists who provide CCS services, and the locally-exercised option of not honoring services provided in substandard or overpriced facilities. The primitive data elements needed to carry out rigorous and routine aggregate and more specific state and local program assessments exist in a common format and could be used to far greater advantage than they have been in the past. If such *were* done, a better approximation of our Plus concept and model would result.

Our models concept has indicated what appears to be a critical structural difference between effective and not-so-effective collections of programs. In fact, we note that as of March 1973, Pennsylvania has recognized this distinction and capitalized on the Plus features of CCS by collapsing all MCHS activities into CCS, thereby capturing some scalar economies in administrative overheads as well as a better measure of control.

Functions performed under MCHS and CCS auspices include investments in facilities and services (especially for various MCHS programs), some slight direct

service provision (special clinics for mentally retarded children provided under the 1967 Child Health Act), and an only partly realized potential for data collection and accountability (CCS almost exclusively). The prime function is making grants so that the states might provide the services themselves, and this is rationalized in terms of the familiar balance wheel or redistribution argument.

Besides the redistributive rationale, which is far and away the most persuasive explanation for both programs, MCHS has some elements of internalizing externalities underlying its existence, particularly as pertains to screening for vision, hearing, and PKU, and to providing immunizations—general services in which the “whole population benefits” argument is salient.

In terms of the process categories of policy invention, execution, and so forth, we must separate our discussion of the two basic programs.

For MCHS, it is clear that the estimation, implementation, evaluation and termination phases have been ill-developed or underdeveloped. Under implementation, what for instance happened to the 10 million or so children who received visual screenings under MCHS auspices in 1972, especially those who were found to have defective vision? Were follow-up and treatment services provided to those in need? Did anyone keep track of the potential users of medical services to see that they received what they required? If other disorders were suspected at the time of visual screening, were the appropriate consultative services and treatments arranged? Deficient implementation in this regard could easily result from the fragmented nature of the services actually provided. Termination, as current events attest, has been largely overlooked; and without any routine determination and evaluation of the applicability and efficiency of MCHS programs, the termination function is being exercised vigorously at White House initiative.

CCS programs are generally well implemented and well estimated (i.e., state directors have a fairly good “sense” of the size of the served populations and what it is costing them to provide services). The primary areas requiring attention are evaluation and termination, and a beginning has been made to carry out evaluations based on comprehensive and common data collected in all the states. Termination or reduction in service, such as it is, is carried out at the state level in response to fluctuating demand for services by children having various disorders and financial requirements. There is no standardized pattern of termination or reduction of service provision from state to state, a fact that has led to incredible variations and inconsistencies regarding kinds of disease and levels of family financial capacity that will be covered, factors which change during the fiscal year as funds are either in ample or scarce supply. Termination or reduction in services then is a fluctuating, capricious activity exercised entirely at the state level.

Medical services represent a mix of models, functions, rationales, and processes, and cannot be adequately described as a single, collective entity. Considering Medicaid, for instance, we see an example of a group of services that approximates our Controllership model, where the prime function is the delegation of service delivery to the states and localities but where most resources, policy/program control, and innovative and stimulative functions derive from the Federal level. These functions have been rationalized basically according to redistribution of resources-welfare arguments. In policy or process terms, there is little evidence that detailed scientific estimation was ever done to determine just how many handicapped individuals at what cost would be eligible for services. Implementation has not been particularly

successful because of coordination problems, inflexible eligibility categories, and other conflicts at the local level of service delivery. It is nearly impossible to evaluate the specific impact of Medicaid on handicapped children because relevant information is collected according to welfare interests and not according to the medical needs of the served population. There are even some questions about evaluating Medicaid as a more general purpose program, an issue attested to by frequent U.S. General Accounting Office probings of specific activities and by the demands that resulted in constructing a new Medicaid Management Information System for the program.

CURRENT MATERNAL AND CHILD HEALTH AND CRIPPLED CHILDREN'S SERVICE PROGRAMS

Maternal and Child Health Service

Background. Amendments to the Social Security Act of 1935 authorized grants to the states for maternal and child health and for health services to crippled children. Demonstration projects were also enabled in the basic 1935 legislation.¹ The fundamental concerns of the Maternal and Child Health Service are roughly characterized as preventive health services, child health supervision, and the fostering of good parent-child relations.

In 1965, amendments to the Social Security Act provided project grants to train professionals in Crippled Children's Services and for so-called "Children and Youth Projects"—comprehensive health services for children in high-density, low-income areas.

The Child Health Act of 1967, once again amending the basic Social Security Act, moved the MCHS further into preventive services (prenatal care, PKU, malnutrition, rubella, etc.), family planning, more comprehensive health services for pre-schoolers, and identification programs. The total current program's services include maternity, medical clinics, (public health) maternity nurses visitations, classes for expectant parents, well-baby clinics, pediatric clinics, school health programs, dental care for children and pregnant women, and immunizations against preventable diseases. The Act also provides for special clinics for mentally retarded children. These clinics, established by a number of states, provide for diagnostic, evaluation, counseling, treatment, and follow-up services. In addition, a proportion of the annual budget is set aside for special projects in support of mentally retarded children.

Budget. The FY 1972 MCHS total budget of \$238,714,000 is broken down in Table 8.4. About 2.5 percent went for research and 6.3 percent was earmarked for personnel training. Ninety percent of the funds were divided about equally between

¹ Title V, Section 501 of the Social Security Act funds the states to provide services for reducing infant mortality and otherwise promoting the health of mothers and children. It also provides the following for crippled children or those who are suffering from conditions leading to crippling: services for locating such children, and for medical, surgical, corrective, and other services, as well as care and aftercare and facilities for diagnosis and hospitalization. A basic source document is U.S. Department of Health, Education and Welfare, *Maternal and Child Health Services of State and Local Health Departments*, MCHS Statistical Series No. 2, 1971 (hereafter referred to as MCHS Statistical Series No. 2).

Table 8.4

MATERNAL AND CHILD HEALTH SERVICE, FY 1972 BUDGET

Type of Service	Expenditures
Grants to states	
Maternal and Child Health Services	\$ 59,250,000
Crippled Children's Services	62,272,000
Project grants	
Maternity and infant care	43,428,000
Children and youth	47,400,000
Dental health of children	1,180,000
Training of service personnel	15,071,000
Research	6,035,000
Direct operational costs of MCHS	4,078,000
Total	\$238,714,000

SOURCE: U.S. Department of Health, Education and Welfare, *Justifications of Appropriation Estimates for Committee on Appropriations--FY 1973*, Vol. I, pp. 223-235.

state grants and project grants. The descriptions and comments in these subsections apply to all of the MCHS programs *except* the Crippled Children's Service state grant program which is discussed separately.

Table 8.5 breaks down the MCHS grants by state. Determination of the individual state grant share is made according to a formula that takes into consideration the number of live births, the state's per capita income, and the number of rural live births. The total available for MCHS grants to all states was \$59,250,000 apportioned to the states according to the described formula. A total of \$4,750,000 from the MCHS grants was set aside for special projects for mentally retarded children.

Service Description. Maternal and Child Health Service activities have a vast diversity of program objectives. To promulgate a policy as broad as "reducing infant mortality and otherwise promoting the health of mothers and children"² is in the literal sense of the expression just like promoting "motherhood." Problems arise in trying to identify programs that are effective in realizing these vague policy objectives. As a result, programs actually undertaken by individual states are numerous, diverse, and generally so dilute the limited available resources that they lose the potential leverage to mount a concerted effort on a manageable subset of the mother and child health problems.

For instance, about 334,000 mothers received services under the Maternity Medical Clinic program in 1971, but this accounts for less than 9 percent of all live births in the United States; expectant parent classes were offered by most of the states, but only 87,760 individuals attended them nationwide in 1970; general pediatric clinics provided services to around 200,000 children in 1970, but this represents only some 0.2 percent of the total population who might have benefited from these services.³ Trying to make comparative programmatic evaluations on a state-by-state basis is a rather unproductive exercise given the number, kinds, and diversity of

² MCHS Statistical Series No. 2, pp. 1-3, quote at p. 1.

³ *Ibid.*

Table 8.5

ALLOCATIONS OF GRANTS FOR MATERNAL AND CHILD HEALTH SERVICES: ACTUAL
(FY 1971) AND ESTIMATED (FY 1973) AWARDS

State	1971 Actual	1973 Estimate
Alabama	\$ 1,247,908	\$ 1,273,000
Alaska	195,461	187,900
Arizona	425,974	434,100
Arkansas	673,478	712,400
California	2,834,834	2,917,600
Colorado	494,248	490,100
Connecticut	475,448	505,300
Delaware	201,995	213,300
D.C.	247,008	251,100
Florida	1,604,726	1,650,400
Georgia	1,654,810	1,654,500
Guam	158,028	158,700
Hawaii	245,422	248,200
Idaho	234,870	246,200
Illinois	1,668,815	1,728,700
Indiana	1,089,353	1,323,700
Iowa	680,398	730,600
Kansas	483,732	500,300
Kentucky	1,133,396	1,173,700
Louisiana	1,361,208	1,374,100
Maine	356,076	342,800
Maryland	1,098,384	1,084,900
Massachusetts	838,403	848,100
Michigan	1,926,890	1,967,000
Minnesota	905,063	934,900
Mississippi	1,085,847	1,077,700
Missouri	1,020,062	1,107,700
Montana	222,453	229,200
Nebraska	346,591	360,700
Nevada	200,211	204,600
New Hampshire	262,881	232,500
New Jersey	1,046,999	1,106,900
New Mexico	340,026	338,600
New York	2,649,381	2,650,400
North Carolina	1,908,325	1,922,500
North Dakota	216,561	218,800
Ohio	2,201,112	2,358,700
Oklahoma	602,965	625,400
Oregon	536,415	554,900
Pennsylvania	2,522,102	2,617,900
Puerto Rico	1,638,916	1,694,800
Rhode Island	273,072	253,700
South Carolina	1,142,005	1,153,500
South Dakota	182,917	229,400
Tennessee	1,236,805	1,245,800
Texas	2,577,513	2,604,700
Utah	435,724	423,300
Vermont	230,921	197,000
Virgin Islands	157,002	157,500
Virginia	1,371,581	1,350,100
Washington	791,559	836,700
West Virginia	761,498	649,600
Wisconsin	1,004,099	1,037,400
Wyoming	204,043	183,000
Total distribution by formula ^a	49,405,514	50,574,500
Special projects for mentally retarded children	4,749,325	4,750,000
Other special projects	5,033,872	5,453,500
Total	\$59,188,711	\$60,778,000

SOURCE: U.S. Department of Health, Education and Welfare, *Justifications of Appropriation Estimates for Committee on Appropriations--FY 1973*, Vol. 1, pp. 276-277.

- ^a(1) One-half of the amount appropriated for each year is apportioned among states on the basis of a uniform grant of \$70,000 and an additional grant in proportion to the number of live births in the state. Amounts awarded must be matched dollar for dollar.
- (2) The remaining half, after being reduced by the amounts reserved for the two categories of special projects, is apportioned by formula. Each state receives an amount which varies directly with the number of urban and rural births in the state and inversely with state per capita income. No state receives less than \$70,000 and rural live births are given twice the weight of urban births.
- (3) The 1973 figures represent tentative apportionment of the amount requested.

programs supported under MCHS and the poor information that is collected at the Federal level to account for these activities.

Let us consider some of the larger classes of MCHS services in more detail.

Support, in whole or part, is given to more than 150 mental retardation clinics to provide diagnosis, evaluation, and the development of a treatment and management plan for the individual child. In addition, 15 special clinics have been established for multiply handicapped children. While these clinics apparently are meeting some individual needs within that population, it is questionable whether these efforts are sufficient to the task. For example, it is estimated that there are roughly 2.5 million children under age 20 who are mentally retarded; however, the mental retardation clinics, a limited program, at best serviced only 57,000 children in 1971, and these services were mostly limited to diagnosis and counseling.⁴

Screening for the prevention of mental retardation because of phenylketonuria (PKU) has been a most successful MCHS undertaking. The tests are simple, inexpensive, and in 1971 were administered to more than nine out of ten newborn children in the United States. It is estimated that this preventive program has discovered one PKU baby in every 16,000 live births, and discovery is the important first step in preventing PKU caused retardation.

The children and youth project grants reached an estimated 400,000 children through 59 projects in 1971.⁵

Millions of children received basic immunizations under MCHS supported programs in FY 1971: smallpox, 1,087,000; pertussis, 1,633,000; tetanus, 2,137,000; polio, 2,204,000; measles, 1,257,000; and rubella, 3,783,000.⁶

Nutritional personnel are supported with MCHS funds and, working through well-baby clinics, pediatric clinics, group practices, and school health programs, over 500 of these specialists have helped reduce the prevalence of malnutrition in rural and economically disadvantaged areas. In this case, as contrasted with PKU screening, the relationship between services provided and actual results in preventing handicapping conditions is not clear-cut or easily measured. We must also wonder about the relative impact possible from the efforts of 500 people, given the size of the rural and economically disadvantaged populations in this country.

Other services provided under MCHS sponsorship are noted in Table 8.6. Of specific interest are the screening programs for visual and hearing defects. Such services are provided with MCHS assistance. In FY 1971, screening programs conducted under the C&Y program found some 14,404 children with visual defects and 5800 children with hearing deficiencies.⁷ Information on rates of referral and follow-up services for youth identified by this program is not generally available. Follow-up activities typically are weaker than those activities designed to identify handicapping conditions.

MCHS and CCS programs together provide for the training and use of paid

⁴ The problems of estimating the numbers of mentally retarded youth are discussed at length in Sec. 10. Information on the mental retardation clinics is from U.S. Department of Health, Education and Welfare, *Justifications of Appropriation Estimates for Committee on Appropriations—FY 1973*, Vol. 1, p. 224 (hereafter referred to as *Justifications of Appropriation Estimates*).

⁵ Secretary's Committee on Mental Retardation, *Mental Retardation Activities*, U.S. Department of Health, Education and Welfare, January 1971.

⁶ The MCHS Statistical Series 3; and U.S. Department of Health, Education and Welfare, *Children Who Received Physician's Services Under the Crippled Children's Program*, MCHS Statistical Series No. 3, 1970.

⁷ *Justifications of Appropriation Estimates*, p. 230.

Table 8.6

EXAMPLES OF SERVICES PROVIDED WITH MCHS SUPPORT, 1971 AND 1973

Service	1971 Provisional	1973 Estimate
Mothers receiving prenatal and postpartum care in maternity clinics	334,000	400,000
Women receiving family planning services	752,000	752,000
Public health nursing visits to Mothers	566,000	566,000
Children	3,290,000	3,290,000
Children attending well child clinics	1,500,000	1,500,000
Children receiving screening tests for Vision	8,977,000	10,000,000
Hearing	5,677,000	6,250,000

SOURCE: U.S. Department of Health, Education and Welfare, *Justifications of Appropriation Estimates for Committee on Appropriations--FY 1973*, Vol. I, p. 225; for more detailed breakdowns, see also U.S. Department of Health, Education and Welfare, *Maternal and Child Health Services of State and Local Health Departments*, MCHS Statistical Series No. 2, 1971.

subprofessional staffs who concentrate their efforts particularly on low income groups. In 1971, more than 660 health-related subprofessional personnel were so trained, and this program is intended to increase for the next several years by about 15 percent annually.

MCHS also participates a little in foreign programs. Personnel exchanges, publications, seminars, and conferences are organized and administered by various MCHS subagencies. P.L. 480 money is also used for cooperative mental retardation studies in a number of countries where the primary emphasis is placed on prevention and identification. Most MCHS funds are not expended on handicapped youth, but rather on ways that may promote health and prevent physical or mental handicaps. The funds expended directly for the handicapped in FY 1971 amount to approximately one-third of the total and are primarily for the Crippled Children's Service grants (\$58,598,000) and for the vision and hearing screening programs and clinics servicing the mentally retarded (a minimum of \$25,000,000). Earlier in this section we identified 81,000 handicapped recipients of MCHS services exclusive of CCS recipients. We have seen no reliable data to estimate the total number of handicaps prevented by the MCHS program.

Comments on the System. Evaluation of state operations under the formula grants segment of MCHS is decentralized to the HEW regional level and is loosely coordinated by MCHS in Washington. This has resulted in much variation between the states, which, under law, are entitled to formulate and implement their own programs. The kinds and extent of this interstate variation were only roughly known by those interviewed at the MCHS in Washington, D.C.; e.g., Montana was cited as "interesting" because of its vigorous Indian Health Services program, Alabama was said to have only slightly developed programs for speech and hearing impaired children, and Mississippi and South Dakota were "thought to be weak in

MCHS programs."⁸ When the issue of quality of services was pursued in the interviews, it was evident that lacking clear performance criteria and lacking basic information for making assessments, the issue of determining overall program quality is a rather academic one—except where state officials take the initiative in collecting evaluation data.

We investigated the extent of MCHS' current evaluation efforts, or more correctly its research budget for these matters. In the Grants Management Office of the Division of Research, MCHS, we found that some \$6 million total is devoted to these activities and that much of the work is vested in one large, ongoing MCHS project under the direction of Professor Weckworth at the University of Minnesota and in a subcontract for data processing and analysis (principally for the reasonably good Crippled Children's state data) at George Washington University under the direction of Margaret Pratt. The latter analysis and data are discussed at the end of this section. One interviewee indicated MCHS "does no in-house evaluations of its own activities" because of budget and staff constraints.⁹

With the exception of the Crippled Children's Service, the present state of the MCHS system may strongly indicate what might happen if our pure Model III, Special Revenue Sharing, Plus, is adopted for programs without maintaining or providing incentives to insure that the Plus, or evaluation component, is well and thoroughly done.

Crippled Children's Service Grant Program

Background The Social Security Act of 1935 also provided for Federal aid to State Crippled Children's Services. Grants-in-aid are given to extend and improve services to crippled children and to those suffering from conditions that lead to crippling. The emphasis is on service to rural and economically depressed areas. Such services are provided as locating crippled children, providing medical, surgical, corrective, and other assistance for diagnosis, hospitalization, and post-hospitalization care. Special demonstration projects are also provided, as is a special contingency fund for mentally retarded programs.

The state share is determined according to a formula that takes into account the number of children under 21, the financial needs of the state (as determined by its per capita income), and the relative number of rural children in the state. States are required to match, on a dollar-for-dollar basis, one-half of the Federal funds; but the other half, including funds for "special projects," is exempted from the matching requirement.¹⁰

Beginning in 1963, CCS began to open up to a wider range of disabilities by relaxing definitions and including additional services in the coverage. The program is now serving many types of handicapped children, not just the crippled. CCS funds

⁸ Interviews with Program Services Branch Staff, MCHS, March 13, 1972. These judgments are meant to be tentative and illustrative; their absolute validity is, of course, open to additional investigation and debate.

⁹ Interviews, Grants Management, Division of Research, MCHS, March 13, 1972. Separate evaluations of the M&I and C&Y programs are produced on occasion. Our major concerns are (1) the slight evaluation of formula grant programs, and (2) the few dollars available for general MCHS evaluations.

¹⁰ For additional details, see U.S. Department of Health, Education and Welfare, *Health Services for Mothers and Children Under Title V, Social Security Act*, MCHS/PHS/DHEW; and Public Health Service, *Services for Crippled Children*, PHS Publication No. 2137.

have never been lavish, but the program has many excellent features, not the least of which is a fairly thorough reporting system—which we draw from in some detail in the succeeding pages.

According to state officials interviewed in a variety of different types of agencies, the Crippled Children's Services represent a particularly bright spot in services to handicapped children generally. We asked ourselves and those involved in administering the program what it was about CCS that made it appear to be relatively successful. The answers suggested were as follows:¹¹

- Medical and other health specialists are used routinely for consultation.
- Medical and health specialists are used for patient care, and the physician-patient relationship is enhanced.
- High standards tend to be maintained through periodic evaluation by peer groups of individual physicians and of the institutions delivering the services and by advisory committees who consider the highest level policies for the program at the state level.
- The program is tailored by each state, is in touch with local needs, and responds flexibly to those needs.
- The program has evolved and is sensitive to changes in the character of the recipient population.
- The "nonpolitical" nature of the program means that it is neither subject to election year vicissitudes nor to general distaste shown by many physicians for welfare-based and oriented care, e.g., Title XIX medical care.
- There is a minimum of administrative overhead, and a maximum of acceptance by the medical community as one of its "own" programs.
- Monitoring and evaluation in terms of requirements for a minimum of comprehensive operational data collection are evident (but not well utilized generally in terms of rigorous analyses and evaluation follow-through.)

The concept of "medical care" has been interpreted in the broadest possible sense, as the CCS program has evolved since 1935, to the point where the programs may include nearly all categories of long-term or chronic illness as well as most services that reasonably might be expected to improve the individual's health condition.

According to one recent assessment,¹² the use of medical advisory committees is one keystone feature of the CCS program, and most CCS directors used this method to guide the planning and administration of their program. Additionally, planning for the total needs of the individual handicapped child is a hallmark function of the CCS program.¹³

¹¹ These generalizations were gleaned from direct interviews in five states and from a careful search through the Rand survey questionnaire responses. Specific references supporting many of these points are H. W. Porterfield, "A Physician Looks at the Crippled Children's Program," *Ohio's Health*, Vol. 23, No. 3, March 1971, pp. 21-24; and H. W. Wallace, R. Cohen, and R. Siffert, "Advisory Committees and Consultants in Programs for Crippled Children," *Public Health Report*, Vol. 83, August 1968, pp. 652-658.

¹² H. W. Wallace et al., *ibid.*

¹³ In our interviews with CCS officials in Illinois and California, we learned, for example, that private physicians in all states often use the CCS planning function on behalf of patients and their families who receive no other assistance from the government; that is, the planning and diagnosis functions or services are important and used even by those who in all other respects are able to provide for their children's needs.

Number and Character of the CCS Population. Table 8.7 shows the number and rate of children receiving physician services (the most prevalent service provided under CCS) for 1950, 1960, and 1970. As compared with the estimated total number of handicapped children in the United States—over 9 million in 1971—the half-million served yearly is not a particularly large proportion; however, the program has shown consistent growth over the years.

Table 8.7

NUMBER AND RATE OF CHILDREN RECEIVING PHYSICIAN SERVICES:
1950, 1960, 1970

Year	Number of Children Served	Rate per 1000 Population ^a
1950	214,405	4.0
1960	354,883	4.9
1970	491,855	6.1

SOURCE: U.S. Department of Health, Education and Welfare, *Children Who Received Physician's Services Under the Crippled Children's Program, FY 1970*, MCHS Statistical Series No. 3, December 1971, p. 7.

^aNumber served per 1000 population under 21 years of age.

Data on the number served are reported in Table 8.8 by age, sex, and race. Note that this program is reaching significant numbers of children under age 5, unlike most other programs for handicapped youth. At a maximum of 75 percent, the relatively low proportion of whites (as compared with their numbers in the general population) indicates that a CCS program objective to reach the economically disadvantaged may in fact be partly realized.

The CCS population receiving physician services is then presented in Table 8.9 according to the state and region where the services are actually provided and according to the children's age cohort. To provide some perspective on the full range of services available under CCS auspices, numbers of children receiving a variety of services are detailed in Table 8.10. From the projections of anticipated future caseload, it is evident that the CCS program is not growing in terms of the number of children served; increased expenditures are largely accounted for in terms of inflationary pressures.

The number of children receiving physician services under CCS has more than doubled in the last two decades from a 1950 level of 214,405 to a 1970 level of 491,855. The total Federal share of this program has increased in the 1960-1972 period from about \$19.5 million to \$62.272 million. The amount of the state contribution to match Federal funds is \$31.136 million. Figure 8.1 shows the relative contributions to CCS from states and localities and the Federal sources over the period.

Variation in Services Provided Based on Age Cohorts. We are concerned with the equity of service provision based on the age cohort of the handicapped child. To illuminate what appears to be considerable variation both within regions and

Table 8.8

AGE, SEX, AND RACE OF CHILDREN RECEIVING PHYSICIAN SERVICES, 1970

Characteristic	Number 1970 ^a	Percent 1970 ^a
Age	491,855	100.0
<1	18,937	3.8
1-4	126,461	25.7
5-9	148,125	30.1
10-14	112,595	22.9
15-17	51,220	10.4
18-20	32,153	6.5
Unknown	2,364	0.6
Sex	491,855	100.0
Male	267,509	54.4
Female	224,003	45.5
Unreported	343	0.1
Race	491,855	100.0
White	328,537	66.8
All others	117,990	24.0
Unreported	45,328	9.2

SOURCE: U.S. Department of Health, Education and Welfare, *Children Who Received Physician's Services Under the Crippled Children's Program, FY 1970*, MCHS Statistical Series No. 3, December 1971, p. 9.

^aCalifornia estimated.

between states regarding the number of children served in various age categories, let us look more carefully at Table 8.9.

Even the most cursory inspection shows variation on a state-by-state basis in the number of those served children within the various cohorts who are receiving physician services. For example, on a percentage basis, New Jersey is serving four times as many children under the age of one than the national average (15.2 percent of the number served versus a national average of 3.8 percent); all of Region 2, of which New Jersey is a part, is picking up nearly twice the national average. On the other hand, Colorado (0.4 percent), Alaska (0.6 percent), Michigan (0.7 percent), and Guam (0.7 percent) are all well below the national average and as much as 380 percent lower than New Jersey. Is it that children in these four jurisdictions, aged one and less, are suffering from fewer handicapping conditions? Perhaps, but a far more satisfying explanation is that New Jersey, Oklahoma (10.8 percent), and several other states are simply working harder to find and serve children in this cohort than are most other states.

Let us repeat the exercise for the other end of the age spectrum—the 18-21 cohort. Nationally, this group represents 6.5 percent of the total recipient population; however, in Kentucky (12.5 percent) it is nearly twice the national average and in Wisconsin (2.9 percent) it is less than half. We do not know why this potentially inequitable difference exists, but it does. A systematic evaluation of the CCS program, the kind of evaluation that generally does not occur at the Federal level, would strive to pin down the exact reasons for the variations and, if indicated, would make remedial recommendations based on those explanations.

Table 8.9

AGE CATEGORIES OF CHILDREN RECEIVING PHYSICIAN SERVICES UNDER THE CCS PROGRAM: BY REGIONS AND STATES--1970

Jurisdiction	Number/Percent in Age Category						
	Total ^a	<1	1-4	5-9	10-14	15-17	18-21
United States	491,855/100%	18,937/3.8%	126,461/25.7%	148,125/30.1%	112,595/22.9%	51,220/10.4%	32,153/6.5%
Region 1	17,990	554/3.0	4,168/23.1	5,552/30.8	4,161/23.1	1,932/10.7	1,351/7.5
Connecticut	3,030	4.0	24.7	29.7	25.0	9.8	5.4
Maine	4,121	2.4	24.2	33.9	19.4	7.2	7.2
Massachusetts	5,156	2.4	19.1	27.6	25.0	14.6	11.4
New Hampshire	1,378	4.4	25.0	33.2	22.9	11.2	3.2
Rhode Island	1,502	4.2	21.4	31.9	23.3	11.3	7.5
Vermont	2,803	2.8	27.4	31.9	23.0	9.1	5.0
Region 2	75,013	5,327/7.1	26,083/34.7	21,059/28.0	14,026/18.7	5,594/7.4	2,818/3.7
New Jersey	7,503	15.2	29.4	27.0	18.4	6.8	2.9
New York	44,458	6.8	35.8	28.0	17.3	7.6	4.2
Puerto Rico	18,858	4.8	37.3	28.3	19.9	6.3	2.8
Virgin Islands	4,167	4.8	21.1	29.2	27.9	12.5	4.4
Region 3	83,762	2,044/2.4	19,795/23.6	27,269/32.5	20,857/24.9	8,879/10.6	4,374/5.2
Delaware	5,225	4.0	28.3	29.4	22.2	9.0	4.0
D.C.	7,759	1.2	24.7	30.2	25.7	12.0	5.9
Maryland	18,229	2.4	20.0	34.5	28.3	10.1	4.3
Pennsylvania	26,330	3.3	24.0	35.8	23.8	9.6	3.3
Virginia	17,789	0.9	26.3	25.4	24.2	11.8	7.2
West Virginia	8,430	3.1	20.7	28.6	23.4	11.9	8.8
Region 4	91,024	3,426/3.8	21,871/24.0	25,296/27.8	20,844/22.9	10,812/11.9	8,361/9.2
Alabama	9,951	2.6	22.9	27.5	25.3	13.0	8.5
Florida	13,670	3.6	21.5	30.4	23.1	11.9	9.3
Georgia	13,230	2.9	18.1	28.1	25.4	13.2	9.3
Kentucky	10,673	5.6	19.9	29.3	19.9	12.7	12.5
Mississippi	5,240	1.9	26.8	26.8	22.4	11.1	10.3
North Carolina	19,075	5.3	32.7	24.8	19.4	10.2	7.4
South Carolina	6,231	2.9	23.4	26.0	24.8	13.0	8.9
Tennessee	12,954	2.9	23.3	28.7	25.2	10.8	8.8
Region 5	62,300	1,783/2.9	15,245/24.5	20,440/32.8	14,443/23.1	6,138/9.8	3,762/6.0
Illinois	12,530	3.2	24.6	31.7	24.1	10.3	6.1
Indiana	7,898	1.7	22.8	30.6	24.0	11.1	9.7
Michigan	16,850	0.7	28.4	31.6	22.3	10.4	6.6
Minnesota	10,774	5.6	21.7	31.5	23.8	8.9	4.4
Ohio	8,772	4.7	25.9	31.8	21.6	9.7	5.5
Wisconsin	5,476	2.0	17.3	46.6	23.7	7.3	2.9
Region 6	35,959	1,401/3.9	8,688/24.2	9,738/27.1	7,883/21.9	4,399/12.2	3,699/10.3
Arkansas	5,176	3.3	28.2	26.9	21.8	12.1	7.6
Louisiana	10,114	2.3	29.1	27.9	21.7	11.1	7.7
New Mexico	3,778	1.5	21.1	30.0	23.2	10.9	9.7
Oklahoma	4,012	10.8	18.4	18.2	17.7	15.7	19.1
Texas	12,879	3.9	21.4	28.3	23.1	12.5	10.8
Region 7	26,416	972/3.7	6,746/25.5	8,327/31.5	5,812/22.0	2,741/10.4	1,588/6.0
Iowa	10,220	4.2	22.3	34.3	23.3	10.4	4.4
Kansas	4,887	3.5	29.6	28.2	21.4	9.4	7.9
Missouri	7,404	3.9	28.9	31.1	20.9	9.5	5.0
Nebraska	3,905	2.2	22.6	29.0	21.5	13.3	9.6
Region 8	12,970	352/2.7	2,933/22.6	4,075/31.4	3,282/25.3	1,449/11.1	805/6.2
Colorado	3,924	0.4	16.8	33.0	29.3	12.6	6.5
Montana	1,276	5.2	31.7	28.1	19.9	10.2	4.8
North Dakota	1,121	2.5	23.8	25.7	24.6	15.5	7.8
South Dakota	2,484	5.4	28.7	32.4	21.1	7.5	4.9
Utah	2,706	1.4	19.0	32.3	27.0	11.9	7.3
Wyoming	1,459	4.8	24.9	31.1	23.8	9.7	5.5
Region 9	71,978	2,574/3.6	17,466/24.3	21,871/30.4	17,671/24.8	7,674/10.7	4,578/6.4
Arizona	7,381	6.8	30.6	31.7	21.6	6.0	3.0
California	58,191	3.4	23.6	29.7	25.2	11.2	6.7
Hawaii	2,886	1.2	23.4	36.3	20.8	10.8	7.4
Nevada	1,642	1.3	35.8	31.0	18.1	9.3	4.0
Guam	1,878	0.7	12.7	35.6	34.5	11.9	4.4
Region 10	14,443	504/3.5	3,476/24.1	4,498/31.1	3,500/24.2	1,602/11.1	817/5.6
Alaska	2,770	0.6	18.4	30.6	31.2	12.9	5.1
Idaho	1,664	5.4	21.4	28.9	23.3	12.3	8.5
Oregon	5,508	4.8	26.9	28.5	22.4	11.3	6.0
Washington	4,501	2.8	25.1	35.5	22.5	9.2	4.4

SOURCE: U.S. Department of Health, Education and Welfare, *Children Who Received Physician's Services Under the Crippled Children's Program, FY 1970*, MCHS Statistical Series No. 3, December 1971, p. 14.

^aTotals do not add to 100% because "unknown age" category has been omitted.

Table 8.10

EXAMPLE SERVICES PROVIDED TO CHILDREN THROUGH CCS SUPPORT,
1971 AND 1973

Type of Service	1971 Provisional	1973 Estimate
Receiving physician services	485,000	500,000
Receiving hospital inpatient care	82,000	82,000
With multiple handicaps	90,000	90,000
With congenital heart disease	33,000	33,000

SOURCE: U.S. Department of Health, Education and Welfare, *Justifications of Appropriation Estimates for Committee on Appropriations--FY 1973*, Vol. 1, p. 226.

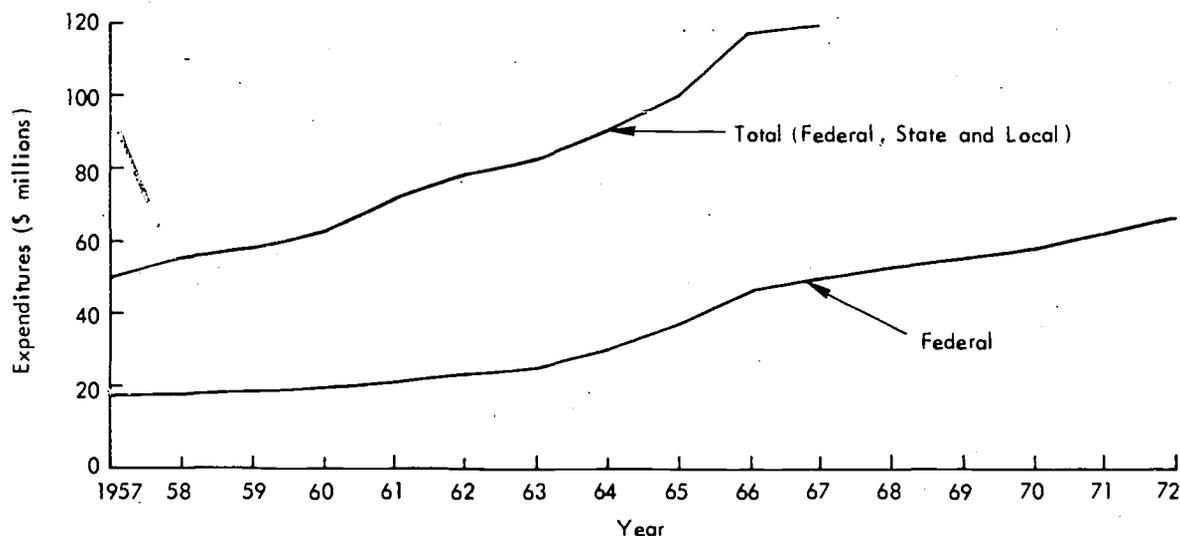


Fig. 8.1—Growth in expenditures for crippled children's services

SOURCE: James W. Moss, *Background Paper on Special Programs for Handicapped Children and Youth for the 1970 White House Conference on Children and Youth*, U.S. Department of Health, Education and Welfare, Office of Education, BEH, December 1970; and U.S. Department of Health, Education and Welfare, *Justification for Appropriation Estimates for Committee on Appropriations*.

Let us consider the distribution of those served for various states for all age cohorts. When the question is asked: "Which states differ significantly from the national pattern?" we find Oklahoma deviating in all age cohorts. It is serving more of those aged one and below and aged 15 to 21, but less of those aged 4 to 14. Does this distribution pattern reflect a better or worse recognition of needs and provision of services (based on age considerations) than the national average or than some other state whose distributional characteristics are considerably different? Again, we do not know the exact answer, but we do know that what Oklahoma is doing for its handicapped children differs significantly from what the rest of the nation and

most other states are doing, based solely on the age of its clients. A routine investigation should be able to assess whether this difference is beneficial, whether or not other states should be informed about it and encouraged to conform to it, or whether Oklahoma should be encouraged to adopt more conventional practices in selecting its CCS population. One expects minor variations in the patterns from state to state, but these cited are far from minor and suggest strongly that important and vastly different operational rules are in force.

Variations are less distinct regionally; although, here too, we can easily see that Region 2 is over-represented for the cohorts aged 4 and below and under-represented for all the rest. Why?

Handicapping Conditions. As shown in Table 8.11, three general classes of disease account for about 70 percent of all reported conditions in the current CCS caseload. The total number of reported conditions (613,023) exceeds the total number of children served (491,855) by an amount roughly approximating the number of multiply handicapped children in the CCS population. It is a rough approximation because we do not know how many children have more than one handicapping condition, more than two, and so on.

Table 8.11

NUMBER OF CONDITIONS IN CHILDREN SERVED BY DIAGNOSTIC CLASS, 1970

International Classification of Disease	Number	Percent of Total
Infective and parasitic diseases	12,016	1.9
Neoplasms	8,265	1.3
Allergic, endocrine system, metabolic and nutritional diseases	6,649	1.0
Diseases of blood and blood-forming organs	2,399	0.3
Mental, psychoneurotic and personality disorders ..	28,013	4.5
Diseases of nervous system and sense organs	148,413	24.2
Diseases of the circulatory system	13,099	2.1
Diseases of the respiratory system	6,083	0.9
Diseases of the digestive system	20,025	3.2
Diseases of the genito-urinary system	4,474	0.7
Deliveries and complications of pregnancy, childbirth, and puerperium	405	0.0
Diseases of the skin and cellular tissue	2,952	0.4
Diseases of the bones and organs of movement	154,854	25.2
Congenital malformations	125,510	20.4
Certain diseases of early infancy	5,238	0.8
Symptoms, senility, and ill-defined conditions	11,373	1.8
Accidents, poisonings, and violence	21,015	3.4
Provisional or deferred diagnosis	12,207	1.9
Examination made, no abnormality reported	30,033	4.8
Total^a	613,023	100.0

SOURCE: U.S. Department of Health, Education and Welfare, *Children Who Received Physician's Services Under the Crippled Children's Program*, FY 1970, MCHS Statistical Series No. 3, December 1971, p. 18.

^aExcludes information for the state of Maine.

The three largest disease classes (diseases of the musculoskeletal system, diseases of the nervous system and sense organs, and congenital malformations) are detailed more specifically in Table 8.12, and in each of the three categories one specific disorder accounts for roughly one-fourth of the total number of conditions reported: for bones, it is flat foot (4.6 percent); for the nervous system, it is cerebral palsy (6.5 percent); and for congenital conditions, it is malformations of the heart (5.3 percent). We observe some 20.9 percent of all the conditions reported are due to flat foot, tibial torsion (another high-ranking bone condition at 4.5 percent), cerebral palsy, and congenital malformations of the heart. This only tells a portion of the story, however; there are literally hundreds of specific disorders covered under the CCS program, even though the relative frequency of many of these is quite small. The Crippled Children's Service has evolved over a lengthy period to become perhaps the most general-purpose medical program extant for handicapped children.

Handicapping Conditions: Variations Among the States. We explored state-by-state variations in the percentages for each major disease condition reported. Table 8.13 shows the average percentage of clients with a particular condition in the United States, and the maximum percentage reported in any state. Note the radical difference in the average and maximum percentages in Table 8.13. We looked at the data in yet another way to begin sketching out individual portraits of state programs. Using the national averages for each disease class, we noted maximum positive and negative deviations from the national "norm" as they occurred in each state. (Table 8.14.) Based on this exercise, we make the following observations: great variations occur across states, all under the umbrella of Crippled Children's Services; and, given the relatively fixed levels of funding in real dollar terms over the last five years, operational choices are being made at the state level to exclude or favor certain disease classes, but we have little or no information about what is happening to the "unfavored" who are denied services in the process.

Calculations made in Table 8.15 provide an example of "early warning" and "attention directing" kinds of assessments that are focused on one appropriate level of detail for Federal consideration. Granted, they are coarse, even qualitative, evaluations based on the crudest of data; however, they do demonstrate one appropriate procedure to begin measuring inequitable or inconsistent performance. One might do the following, for example:

- Establish a national reference or standard and then calculate deviations from it (assume at first approximation homogeneity of distributions of disease or handicapping conditions throughout the country).
- Next, routinely conduct a survey of the handicapped population to develop weighting factors to account for unique and/or persistent differences on an interstate basis.
- Systematically carry out follow-on assessments to provide information that in turn could be used to improve the equity and consistency of service delivery.

We next considered recent trends for the three most prevalent disease classes in the CCS caseload by tallying both relative frequency and percentage distributions for them for 1968, 1969, and 1970. As shown in Table 8.16, the relative percentage distribution among these classes has remained essentially unchanged in these years; however, note that the absolute counts took an impressively large upward jump of

Table 8.12

NUMBER AND PERCENT OF CONDITIONS REPORTED, 1970

Type of Condition	Number	Percent of Total
Diseases of the Bones and Organs of Movement		
Rheumatoid arthritis and allied conditions	1,831	0.2
Osteomyelitis and periostitis	1,557	0.2
Legg-(calve)-Perthes (disease)	3,702	0.6
Slipped femoral epiphysis, nontraumatic	1,262	0.2
All other osteochondrosis	2,580	0.4
Craniostenosis	425	0.0
Certain other diseases of the bones and organs of movement	3,145	0.5
All other diseases of the bone and joint	3,914	0.6
Progressive muscular dystrophy	1,522	0.2
Curvature of the spine	12,525	2.0
Flat foot	28,513	4.6
Hallux valgus and varus	1,821	0.2
Metatarsus Varus	13,868	2.2
Clubfoot	20,953	3.4
Tibial torsion	28,067	4.5
Genu valgum and genu varum	13,679	2.2
All other diseases of the musculoskeletal system	15,490	2.5
Total ^a	154,854	25.2
Diseases of the Nervous System and Sense Organs		
Vascular lesions affecting central nervous system	412	0.0
Late effects of intracranial abscess or pyogenic infection	1,395	0.7
Multiple sclerosis	40	0.0
Cerebral palsy	40,420	6.5
Epilepsy	17,666	2.8
All other diseases of the nervous system	5,323	0.8
Refractive errors	8,519	1.3
Strabismus	15,903	2.5
Blindness	601	0.0
All other diseases of the eye	5,147	0.8
Otitis media without mention of mastoiditis	17,139	2.7
Mastoiditis with or without mention of otitis media	1,055	0.1
Conductive hearing impairment	11,003	1.7
Sensory-neural hearing impairment	12,833	2.0
Other central nervous system condition resulting in hearing impairment	791	0.1
All other hearing impairments	6,835	1.1
All other diseases of the ear and mastoid process	3,331	0.5
Total ^a	148,413	24.2
Congenital Malformations		
Spina bifida and meningocele	7,968	1.2
Congenital hydrocephalus	5,057	0.8
Congenital cataract	1,425	0.2
Congenital ptosis of lid (eye)	677	0.1
Congenital malformations of the ear	1,698	0.2
Congenital malformations of the heart	32,683	5.3
Congenital malformations of great vessels	4,679	0.7
All other congenital malformations of circulatory system	2,554	0.4
Cleft palate (including submucosal) only	6,742	1.0
Cleft lip only	2,932	0.4
Both cleft palate (including submucosal) and cleft lip	13,307	2.1
Congenital hypertrophic pyloric stenosis	206	0.0
Imperforate anus	742	0.1
Congenital deformity of intestine (any part)	349	0.0
Congenital absence or atresia of bile duct (any)	59	0.0
Tracheo-esophageal fistula	326	0.0
All other congenital malformations of the digestive system	1,151	0.1
Undescended testicle	706	0.1
Epipladias and hypospadias	1,311	0.2
All other congenital malformations of the genito-urinary system	2,829	0.4
Congenital dislocation of hip	9,628	1.5
Chondrodystrophy	814	0.1
Osteogenesis imperfecta	622	0.1
Congenital limb deficiencies	3,032	0.4
All other congenital malformations of bone and joint	10,227	1.6
Webbed fingers and/or toes	1,758	0.2
All other congenital malformations	12,028	1.9
Total ^a	125,510	20.4

SOURCE: U.S. Department of Health, Education and Welfare, *Children Who Received Physician's Services Under the Crippled Children's Program, FY 1970*, MCHS Statistical Series No. 3, December 1971, pp. 18-19.

^aExcludes information for the state of Maine.

Table 8.13
 MAXIMUM REPORTED RATES FOR DISEASE CLASSES/TOTAL CONDITIONS
 REPORTED IN 1970

Disease Class/Condition	Number Reported	Percent National Average	Maximum Percent in Disease Class/Condition in Any State
Diseases of nervous system and sense organs	148,413	24.2	39.6 Wisconsin
Congenital malformations	125,510	20.4	39.8 Connecticut, Idaho
Diseases of bones and organs of movement	154,854	25.2	52.1 Vermont
Accidents, poison, violence	21,015	3.4	9.3 Texas
Certain diseases of early infancy	5,238	0.8	5.3 Oklahoma
Mental, psychoneurotic and personality disorders	28,013	4.5	21.3 Iowa
Diseases of the digestive system	20,025	3.2	20.7 Oklahoma
Diseases of the circulatory system	13,099	2.1	15.6 Rhode Island
Diseases of the respiratory system	6,083	0.9	11.3 Oklahoma
Neoplasms	8,265	1.3	2.5 Texas
Infective and parasitic diseases	12,016	1.9	9.6 Texas
Allergic, endocrine, metabolic and nutritional diseases	6,649	1.0	3.6 Indiana
Diseases of blood and blood-forming organs	2,399	0.3	1.2 New York
Genito-urinary	4,474	0.7	3.1 Rhode Island
Skin and cells	2,952	0.4	1.2 Oklahoma
Examinations	54,018	8.8	35.3 Utah
Total	613,023	100.0	

SOURCE: Recomputed from U.S. Department of Health, Education and Welfare, *Children Who Received Physician's Services Under the Crippled Children's Program, FY 1970*, MCHS Statistical Series No. 3, December 1971.

16 percent in 1970. The data collection system in 1969 (therefore the 1970 report) was standardized and made machine-processible. Rather than approximating the load, as had been the case until then, the states were required to make an accurate count.

Regional differences in rates reported and served are illustrated in Table 8.17 for the top three disease classes. As compared with the national average, we see that for diseases of the nervous system, Regions 1 and 7 are considerably lower (15.6 percent of those served versus a United States average of 24.2 percent) and Region 3 (31.0 percent) is considerably higher. What begins to explain interregional differences as large as this? For diseases of the bones and organs of movement, Region 2 at 36.1 percent of its load surpasses the national average of 25.2 percent and nearly triples Region 9's 11.2 percent contribution. The same striking range exists for congenital malformations: Region 2 reports and serves some 15.1 percent, while nationally this value is 20.4 percent, and in Region 7 it is 27.5 percent.

For a program with national funding and nationally stated objectives, many people would expect consistent and equitable provision of services. These interregional comparisons and the interstate comparisons made earlier, however, strongly indicate that both considerable inequities and inconsistencies do exist, including no service going to certain types of handicapped youth in some states. To determine specifically why these differences should be so marked would require more detailed inquiries than those we were asked to accomplish in this research. More importantly, it would require some institutional mechanism at the national level to insure that

Table 8.14

CCS PROGRAMS: STATE CHARACTERISTICS DEVIATING SIGNIFICANTLY FROM NATIONAL PROFILE, 1970

Region/ State	Major Positive Deviations	+Δ%	Major Negative Deviations	-Δ%	General Overview Comments on Character of Services Provided
Region 1	Bones	+11.4	Nervous	- 9.5	Eyes and ears are uniformly under-represented in favor of more conventional bone (crippled children) disorders
Connecticut	Congenital Circulatory	+19.4 + 5.3	Bones and organs of movement Nervous	-19.4 - 9.5	Emphasis on congenital circulatory disorders; deemphasis on diseases of bones and organs of movement and nervous system disorders (particularly eyes and ears).
Maine ^a					
Massachusetts	Digestive, general Cerebral palsy	+ 5.5 + 3.3	Nervous, general Eye Hearing Ear and mastoid	- 7.7 - 4.3 - 3.9 - 3.5	Corresponds to national averages with following minor exceptions: emphasis on digestive diseases and cerebral palsy; deemphasis on nervous system, general (specifically diseases of eye, ear and hearing impairment).
New Hampshire	Bones	+13.0	Nervous, general Eye Ear	- 7.1 - 4.9 - 3.0	Corresponds to national averages with following exceptions: emphasis on bone diseases; deemphasis on nervous system, general (specifically diseases of eye or ear).
Rhode Island	Circulatory Bones	+13.5 +11.7	Nervous Eye	-14.9 - 4.9	Emphasis on circulatory and bones; deemphasis on nervous system (specifically eye diseases).
Vermont	Bones	+24.9	Nervous	- 7.3	Large emphasis on bones (specifically club and flat foot); deemphasis on all other services, especially nervous systems (specifically eyes, hearing impairment--better than national average).
Region 2	Bones	+10.9	Congenital	- 5.3	No clear patterns because of disparities between individual limits of observation in Region 2.
New Jersey	Congenital	+11.5			Specific congenital emphasis; deemphasis general on all others.
New York	Bones Flat foot	+13.5 + 6.3	Congenital, general	- 5.6	Emphasis on bones (particularly flat feet); slight deemphasis on congenital, general and mental, psychoneurotic, personality disorders.
Puerto Rico	Bones Eye	+14.4 + 8.2	Congenital, general	- 8.0	Emphasis on bones and eye diseases; congenital and all others generally lower.
Virgin Islands	Digestive Nervous Respiratory	+ 9.6 + 6.5 + 4.4	Congenital Bones	-18.3 - 9.1	While nervous system generally higher than average, eye disorders considerably better than expected; congenital problems are essentially overlooked.
Region 3	Nervous	+ 6.8	Bones	- 4.1	
Delaware	Bones Respiratory	+ 7.4 + 5.9	Congenital	- 7.0	Bones and respiratory problems are considered at slightly greater rate than congenital, but generally conform to national average.
D.C.	Nervous Eye Examinations	+14.2 +21.9 +11.5	Congenital	-13.2	Far better than average nervous system program, particularly eyes, taken with increased emphasis on examinations; eye identification program done at relative general expense of congenital disorders.
Maryland	Nervous Eye Mental	+13.1 +10.3 + 4.5	Congenital	-14.0	
Pennsylvania	Nervous	+ 7.6			General reduction in all others except congenital and bones, which are approximately at national average.
Virginia					Conforms to rate average.
West Virginia					Conforms to rate average.
Region 4	Bones	+ 5.0			Conforms to averages, but slightly more to bones.
Alabama	Nervous Eye	+13.1 + 5.7	Congenital	- 5.3	
Florida	Bones	+12.0	Nervous	-11.8	All others conform.
Georgia	No significant deviations		Examinations Digestive	- 7.7 - 2.7	
Kentucky					Generally conforms. Nervous + (eyes); congenital (-); bones (+).
Mississippi	Bones Cerebral palsy	+ 9.1 + 7.7	Eyes Ears	- 3.3 - 3.5	
North Carolina	Bones	+15.6	Nervous Eye Congenital	-10.1 - 4.9 - 5.3	
South Carolina	Circulatory	+ 7.3	Nervous Eye	- 6.4 - 4.7	Slight nervous; emphasis on rheumatic fever program.
Tennessee			Examinations	- 7.2	Conforms to national averages.

Table 8.14--continued

Region/ State	Major Positive Deviations	+Δ%	Major Negative Deviations	-Δ%	General Overview Comments on Character of Services Provided
Region 5					About like nationals, minor variables
Illinois	Congenital	+ 4.5	Bones	- 6.8	Emphasis on congenital.
Indiana	Congenital Mental Digestive	+ 5.3 + 4.0 + 3.5	Bones	-12.2	Emphasis on congenital, mental, digestive.
Michigan	Eyes	+ 9.6			Close to average: more nervous (eyes), less congenital.
Minnesota					No explanation why so many multiples identified; e.g., examination rate only slightly greater than normal.
Ohio	Congenital All other	+11.2 + 6.5			Nerves and general diseases.
Wisconsin	Nerves Hearing	+15.4 +20.0			Nervous way up (not eyes which are less than expected, but ears--heavy on impairment +20%, diseases of ear +4.5). Done to virtual exclusion of circulatory, respiratory, allergy, blood, genito-urinary, and skin which altogether had only 25 conditions reported.
Region 6	No pattern		Nervous	- 8.0	Nervous (small eye and ear program); cerebral palsy high. Infective high (polio mainly, 640 expected, 2191 reported).
Arkansas	Bones	+11.4	Nervous	-10.3	Small eye or ear program (cerebral palsy accounts for bulk of nervous).
New Mexico					No major deviations.
Oklahoma	Digestive Respiratory	+17.5 +10.4	Nervous Congenital Bones	-14.4 -15.2 -19.6	Nervous (small eye and ear programs); small congenital and bones. Large digestive and respiratory programs (largest in sample). Digestive 986 reported, 151 expected; respiratory 536 reported, 43 expected.
Texas	Congenital Circulatory	+15.0 + 9.0	Nervous	- 9.7	Nervous (small eye and ear programs); extraordinary heart program.
Region 7	Congenital Circulatory Mental	+ 7.1 + 5.9 + 9.0	Nervous	- 8.6	Nervous (eye and ear namely).
Iowa	Mental Other mental	+16.8 + 7.6	Bones	-16.1	Psychological mental disorders at expense of bones.
Kansas	Bones Club foot All other	+21.9 + 7.0 + 6.6	Nervous Congenital	-15.9	Eye and ear: 13 reported versus 898 expected. Club foot favored.
Missouri	Congenital	+11.3	Nervous	- 9.6	Nervous (small eye and ear programs). Congenital, cleft palate.
Nebraska	Congenital Circulatory Bones Mental Other mental	+16.0 + 9.7 + 5.7 + 5.6 + 5.2	Nervous	-12.2	Nervous (small eye and ear programs); more cerebral palsy than expected (691 expected, 146 reported). All increased: allergy, blood, genito-urinary, respiratory. Congenital-circulatory and cleft palates.
Region 8					No major variations.
Colorado	Nervous Hearing	+14.5 +10.0	Bones	- 6.4	Nervous (good ear program). Bones generally less, others less.
Montana	Bones Congenital Cleft palate	+10.0 + 8.6 + 7.0	Nervous	- 5.3	Eyes and ears less emphasized than bones and cleft palate.
North Dakota	Congenital Cleft palate Digestive Occlusion	+15.0 + 8.2 + 8.5 + 9.2	Nervous	-11.6	Occlusion and cleft palate in favor of eyes and ears, others.
South Dakota	Bones Flat foot Club foot	+24.4 + 6.3 +11.1	Nervous	- 9.2	Small ear and epilepsy programs; large club foot program.
Utah	Examinations Mental	+26.5 + 9.4	Nervous Congenital Bones	- 9.2 - 8.7 -11.8	
Wyoming					No major variations.

Table 8.14--continued

Region/ State	Major Positive Deviations	+Δ%	Major Negative Deviations	-Δ%	General Overview Comments on Character of Services Provided
Region 9	Nervous Examinations	+ 3.8 +10.2	Bones	-14.0	+ eyes, ears, cerebral palsy, examinations. - club and flat foot; valgus, varus. No major variations.
Arizona					
California	Examinations Nervous	+12.4 + 4.3	Bones	-16.7	No mental at all in CCS. Mostly eyes and ears and range of other disorders at expense of bones (valgus and varus; flat foot).
Hawaii	Mental Nervous Circulatory	+ 9.1 + 4.5 + 4.1	Bones	-10.6	Nervous (ears); mental greater than bones. Rheumatic fever.
Nevada	Congenital Circulatory Circulatory	+ 7.3 + 5.8 + 5.2	Nervous	- 5.1	Small ear program, eyes OK. Circulatory system favored.
Guam	Nervous Eyes Ears	+19.2 + 8.9 +13.8	Bones Congenital	-19.3 - 8.1	Ear and eye programs outstanding, examinations OK. Bone and joint weak. Spina bifida.
Region 10	Congenital	+ 5.8	Bones	- 6.7	+ ears and mastoid; circulatory. - flat foot, digestive, epilepsy.
Alaska	Nervous Eyes Ears Examinations	+25.0 + 8.4 +23.3 + 5.2	Congenital Bones	- 9.6 -12.0	
Idaho	Congenital Circulatory Cleft palate	+19.4 + 8.6 +10.8	Bones	-10.7	
Oregon	Congenital Mental	+11.1 + 6.2	Nervous Bones	- 8.3 - 5.1	Small eye and ear programs.
Washington	Nervous Ears Congenital Cleft palate	+11.5 +12.8 + 3.0 + 7.2			Ears and cleft palates. Few visually or epilepsy handicapped children. General diminution in others (mental, digestive).

^aNo data.

investigations of major discrepancies are carried out routinely in the future and action taken on the results of those inquiries, if so indicated.

Consider the variation in multiple conditions reported in Table 8.18 for the various states. Ranging from a low of 2.6 percent reported having multiple handicaps in Rhode Island to a high of 53.5 percent in Minnesota and 49.0 percent in Iowa, these variations are quite different from the national average of 18.5 percent of the CCS caseload. Explanations of this vast variation in the identification of multiple handicaps are that certain states might not choose to report secondary handicaps unless they are nearly as marked as the primary handicap; certain states may simply choose to serve more multiply handicapped, or certain states have more well-developed identification programs than others. For example, Iowa and Minnesota have expended a considerable portion of their CCS funds on the identification or case-finding service. (Iowa also has a strong program for mental retardation.)

Since the second portion of this research will concentrate on aural and visual handicaps, the numbers of each in the CCS caseload are presented in Table 8.19. Of the 491,855 reported to be receiving services under CCS, some 13.4 percent or 82,144 were reported as having some sort of aural or visual impairment. We consider this a conservative estimate based on our earlier observation about the wide variation in reporting of multiply handicapped children on a state-by-state basis.

Table 8.15

SUMMARY, CCS PROGRAMS: STATES RANKED BY MAXIMUM POSITIVE AND NEGATIVE DEVIATION FROM NATIONAL AVERAGE FOR TOP THREE DISEASE CLASSES, 1970

Rank	Diseases of Nervous System and Sense Organs		Diseases of Bones and Organs of Movement		Congenital Malformations	
	Number	Percent	Number	Percent	Number	Percent
	National Average		National Average		National Average	
	148,413	24.2	154,854	25.2	125,510	20.4
	Rank		Rank		Rank	
Maximum Positive Deviation						
1	Alaska	1,685	49.2	1,855	52.1	1,606
2	Guam	888	43.4	1,346	49.6	742
3	Wisconsin	2,394	39.6	3,142	47.1	1,864
4	Colorado	1,849	38.7	9,316	40.8	415
5	D.C.	3,724	38.2	9,996	39.6	4,755
6	Alabama	5,158	37.3	17,849	38.7	2,710
6	Maryland	8,655	37.3	571	38.2	3,079
8	Washington	1,727	33.7	2,414	37.6	3,712
9	Pennsylvania	34	31.8	7,779	37.2	2,488
10	Virgin Islands	1,526	30.7	569	36.9	496
Maximum Negative Deviation						
1	Kansas	554	8.3	122	5.9	108
2	Rhode Island	144	9.3	317	6.6	251
3	Oklahoma	469	9.8	281	8.2	1,507
4	Florida	2,511	12.0	5,382	8.5	709
4	Nebraska	618	12.0	1,713	9.1	371
6	North Dakota	148	12.6	377	12.4	356
7	Arkansas	1,029	13.9	1,563	13.0	253
8	North Carolina	3,235	14.1	558	13.8	3,127
9	Texas	1,952	14.5	270	14.5	997
10	Connecticut	593	14.7	803	16.1	854

Table 8.16

CCS: THREE MOST SIGNIFICANT DISEASE CLASSES REPORTED, 1968, 1969, 1970

Disease Class	1968		1969		1970	
	Number	Percent	Number	Percent	Number	Percent
Diseases of nervous system and sense organs	123,000	22.7	126,000	23.7	148,413	24.2
Disease of bones and organs of movement	139,000	25.7	134,000	25.2	154,854	25.2
Congenital malformations	110,000	20.3	109,000	20.5	125,510	20.4
Totals for all conditions reported, all children, all diseases	540,000	100.0	530,000	100.0	613,023	100.0

Table 8.17

TOTAL CONDITIONS AND TOP THREE DISEASE CLASSES IN CCS PROGRAM BY REGION, 1970

Nation/ Region	Total Conditions Reported	Nervous System and Sense Organs		Bones and Organs of Movement		Congenital Malformations	
		Number	Percent	Number	Percent	Number	Percent
Nation	613,023	148,413	24.2	154,854	25.2	125,510	20.4
Region 1 ^a	17,696	2,767	15.6	5,486	31.0	4,433	25.0
Region 2	84,736	20,072	23.6	30,670	36.1	12,808	15.1
Region 3	102,339	31,761	31.0	24,197	23.6	16,774	16.3
Region 4	126,834	28,090	22.1	38,343	30.2	24,875	19.6
Region 5	88,866	22,260	25.0	19,367	21.7	21,021	23.6
Region 6	40,367	6,576	16.2	11,185	27.7	9,306	23.0
Region 7	40,275	6,294	15.6	9,391	23.3	11,108	27.5
Region 8	15,168	3,556	23.4	4,005	26.4	3,071	20.2
Region 9	78,445	22,024	28.0	8,823	11.2	17,312	22.0
Region 10	18,297	5,013	27.3	3,387	18.5	4,802	26.2

SOURCE: Retabulated and reorganized from U.S. Department of Health, Education and Welfare, *Children Who Received Physician's Services Under the Crippled Children's Program, FY 1970*, MCHS Statistical Series No. 3, December 1971, passim.

^aExcludes data from Maine.

Table 8.18

TOTAL CHILDREN WITH MULTIPLE CONDITIONS AND TOTAL NUMBER OF CONDITIONS BY STATE
AND REGION, 1970

Nation/Region	Total Children Served	Percent with Multiple Conditions	Conditions per 1000 Population
United States ^a	491,855	18.5	7
Region 1 ^a	17,990	15.5	4
Connecticut	3,030	22.5	3
Maine	4,121	0.0	--
Massachusetts	5,156	26.1	3
New Hampshire	1,378	7.2	5
Rhode Island	1,502	2.6	5
Vermont	2,803	22.0	20
Region 2	75,013	11.0	8
New Jersey	7,530	11.0	3
New York	44,458	3.3	7
Puerto Rico	18,858	28.0	17
Virgin Islands	4,167	16.6	--
Region 3	83,762	16.9	11
Delaware	5,225	30.1	32
D.C.	7,759	19.4	31
Maryland	18,229	20.3	15
Pennsylvania	26,330	16.1	7
Virginia	17,789	3.3	10
West Virginia	8,430	30.4	18
Region 4	91,024	28.7	10
Alabama	9,951	29.1	9
Florida	13,670	36.6	9
Georgia	13,230	36.1	10
Kentucky	10,673	39.2	13
Mississippi	5,240	20.5	6
North Carolina	19,075	16.2	11
South Carolina	6,231	23.1	7
Tennessee	12,954	28.6	11
Region 5	62,300	26.9	5
Illinois	12,530	39.3	5
Indiana	7,898	36.5	6
Michigan	16,850	3.0	5
Minnesota	10,774	53.5	14
Ohio	8,772	25.1	3
Wisconsin	5,476	9.2	3
Region 6	35,959	9.3	5
Arkansas	5,176	29.5	9
Louisiana	10,114	5.4	6
New Mexico	3,778	8.3	9
Oklahoma	4,012	11.2	5
Texas	12,879	4.0	3
Region 7	26,416	34.8	9
Iowa	10,220	49.0	17
Kansas	4,887	29.4	7
Missouri	7,404	24.6	5
Nebraska	3,905	23.7	9
Region 8	12,970	13.0	7
Colorado	3,924	15.1	6
Montana	1,276	26.4	6
North Dakota	1,121	4.5	5
South Dakota	2,484	8.2	10
Utah	2,706	8.2	6
Wyoming	1,459	19.0	14
Region 9	71,978	7.7	9
Arizona	7,381	10.7	11
California	58,191	6.6	8
Hawaii	2,886	21.8	11
Nevada	1,642	8.8	9
Guam	1,878	8.0	40
Region 10	14,443	20.3	7
Alaska	2,770	19.7	25
Idaho	1,664	11.2	6
Oregon	5,508	30.0	10
Washington	4,501	12.1	4

SOURCE: U.S. Department of Health, Education and Welfare, *Children Who Received Physician's Services Under the Crippled Children's Program, FY 1970*, MCHS Statistical Series No. 3, December 1971, p. 17.

^aExcludes information for the state of Maine.

Table 8.19

VISUAL AND AURAL DISEASES: CCS CASELOAD, 1970

Type of Disease	Percent of Total CCS Caseload	Number of Conditions
Visual		
Refractive errors	1.3	
Strabismus	2.5	
Blindness	0.1	
All other eye diseases	0.8	
Congenital cataract	0.2	
Congenital ptosis (eye)	0.1	
Total	5.0	30,651
Aural		
Otitis media without mention of mastoiditis	2.7	
Mastoiditis	0.1	
Conductive hearing impairment	1.7	
Sensory-neural hearing impairment	2.0	
Other central nervous impairment resulting in hearing loss	0.1	
All other hearing impairments	1.1	
All other diseases of the ear and mastoid ..	0.5	
Congenital malformations of ear	0.2	
Total	8.4	51,493
Total visual and aural	13.4	82,144

SOURCE: U.S. Department of Health, Education and Welfare, *Children Who Received Physician's Services Under the Crippled Children's Program, FY 1970*, MCHS Statistical Series No. 3, December 1971, Tables 14 and 15 abstracted.

Budget. Actual and estimated grant allocations for the various states for FY 1971 and 1973, respectively, are presented in Table 8.20. To collect much of the information on the CCS program and to put the program into the broader context of the total handicapped population of children, Table 8.21 presents the following data: the size of each state's population aged 0-21, the number of CCS children in each state, the number of CCS dollars expended in each state, the per capita expenditure on a state basis for CCS children, and other illustrative calculations.

Information presented in this table in columns 5 and 6 again emphasizes state-by-state variation. In fact, on a raw per capita basis of total state population aged 0-21 we see that the Federal expenditures range from a high in Alaska of \$1.28 to a low in California of \$0.31, as compared with a national average expenditure per young person of \$0.69. When considering the per client Federal expenditures for the CCS caseload on a state-by-state basis, the discrepancies are even more pronounced. As shown in column 6, the average per client expenditures range from \$26.90 in Washington, D.C., to \$249.17 in Ohio, as compared with a national average of \$117.76. CCS serves a small percentage of the handicapped youth aged 0-21 in each state; the percentage varies widely across states. Why these variations exist is not clear, but they are related to differences in the relative wealth of the states and the number of live births in each per annum (the basic factors considered in the formula

Table 8.20

ALLOCATIONS OF GRANTS FOR CRIPPLED CHILDREN'S SERVICES: ACTUAL (FY 1971) AND ESTIMATED (FY 1973) AWARDS

State	1971 Actual	1973 Estimated
Alabama	\$ 1,233,750	\$ 1,334,500
Alaska	190,886	187,400
Arizona	453,155	489,900
Arkansas	764,797	802,000
California	2,525,849	2,820,100
Colorado	447,187	556,900
Connecticut	506,134	550,300
Delaware	213,463	219,300
D.C.	220,212	231,300
Florida	1,412,687	1,566,300
Georgia	1,532,393	1,647,100
Guam	273,999	154,900
Hawaii	320,945	248,500
Idaho	276,339	292,800
Illinois	1,528,560	1,797,800
Indiana	1,241,567	1,461,800
Iowa	754,187	894,100
Kansas	559,493	611,300
Kentucky	1,183,600	1,306,100
Louisiana	1,256,709	1,316,900
Maine	336,140	356,100
Maryland	723,483	843,400
Massachusetts	789,336	912,300
Michigan	1,737,632	2,013,700
Minnesota	956,268	1,127,800
Mississippi	1,079,784	1,115,700
Missouri	1,065,628	1,219,900
Montana	289,988	261,000
Nebraska	399,551	460,400
Nevada	266,705	208,100
New Hampshire	243,654	245,300
New Jersey	981,662	1,094,700
New Mexico	330,493	364,000
New York	2,245,364	2,505,200
North Carolina	1,974,387	2,133,000
North Dakota	242,699	274,500
Ohio	2,206,790	2,510,000
Oklahoma	666,832	759,000
Oregon	533,302	591,700
Pennsylvania	2,368,601	2,717,100
Puerto Rico	1,465,042	1,581,400
Rhode Island	250,764	262,100
South Carolina	1,115,709	1,185,600
South Dakota	248,501	278,800
Tennessee	1,285,940	1,439,500
Texas	2,561,876	2,904,500
Utah	297,465	343,100
Vermont	207,827	206,000
Virgin Islands	148,560	150,700
Virginia	1,424,748	1,487,700
Washington	689,782	805,000
West Virginia	717,319	740,200
Wisconsin	1,049,513	1,262,300
Wyoming	171,983	188,400
Total distribution by formula	47,974,240	53,037,500
Special projects for mentally retarded children	4,998,967	5,000,000
Other special projects	5,624,412	6,862,500
Total	\$58,597,619	\$64,900,000

SOURCE: U.S. Department of Health, Education and Welfare, *Justifications of Appropriation Estimates for Committee on Appropriations--FY 1973*, Vol. I, pp. 278-279.

- NOTE:
- o One-half of the amount appropriated for each year is apportioned among states on the basis of a uniform grant of \$70,000 and an additional grant in proportion to the number of children under 21 years in the state. Amounts awarded must be matched dollar for dollar.
 - o The remaining half, after being reduced by the amounts reserved for the two categories of special projects, is apportioned by formula. Each state receives an amount which varies directly with the number of children under 21 years in urban and rural areas in the state and varies inversely with state per capita income. No state receives less than a specific minimum amount and children in rural areas are given twice the weight of those in urban areas.
 - o The 1973 figures represent tentative apportionment of the amount requested.

Table 8.21

CCS PROGRAMS: 1970 SUMMARY TABLE

(1) State	(2) 1970 Population Aged 0-21	(3) CCS Clients	(4) CCS Expenditures	(5) Expenditures per Population Aged 0-21	(6) Federal Expenditures per Client
United States	83,778,877	491,855	\$57,922,348	\$.69	\$117.76
Alabama	1,480,251	9,951	1,261,328	.85	126.75
Alaska	145,455	2,770	186,474	1.28	67.32
Arizona	770,854	7,381	441,626	.57	59.83
Arkansas	783,832	5,176	779,344	.99	150.57
California	8,051,260	58,191	2,487,985	.31	42.76
Colorado	950,355	3,924	438,585	.46	111.77
Connecticut	1,208,449	3,030	490,098	.38	161.75
Delaware	234,349	5,225	197,938	.84	37.88
D. C.	286,853	7,759	208,684	.73	26.90
Florida	2,533,230	13,670	1,368,802	.54	100.13
Georgia	1,988,295	13,230	1,521,406	.76	115.00
Guam	---	1,878	214,244	---	114.08
Hawaii	337,173	2,886	374,602	1.11	129.80
Idaho	313,037	1,664	274,758	.87	165.12
Illinois	4,522,500	12,530	1,501,427	.33	119.83
Indiana	2,205,477	7,898	1,232,207	.56	156.02
Iowa	1,167,415	10,220	750,104	.64	73.40
Kansas	915,398	4,887	559,999	.61	114.59
Kentucky	1,355,262	10,673	1,174,184	.87	110.01
Louisiana	1,661,215	10,114	1,226,011	.74	121.22
Maine	411,998	4,121	316,556	.77	76.82
Maryland	1,643,729	18,229	747,876	.45	41.03
Massachusetts	2,275,801	5,156	748,551	.33	145.18
Michigan	3,869,345	16,850	1,713,636	.44	101.70
Minnesota	1,644,079	10,774	1,014,713	.62	94.18
Mississippi	1,010,096	5,240	856,115	.85	163.38
Missouri	1,867,264	7,404	1,057,691	.57	142.85
Montana	300,507	1,276	306,620	1.02	240.30
Nebraska	613,276	3,905	392,767	.64	100.58
Nevada	199,481	1,642	244,432	1.23	148.86
New Hampshire	306,671	1,378	236,748	.77	171.81
New Jersey	2,806,616	7,530	971,152	.35	128.97
New Mexico	478,840	3,778	339,338	.71	89.82
New York	6,999,940	44,458	2,212,403	.32	49.76
North Carolina	2,177,308	19,075	1,964,945	.90	103.01
North Dakota	272,641	1,121	249,531	.92	222.60
Ohio	4,462,904	8,772	2,185,722	.49	249.17
Oklahoma	1,018,010	4,012	657,261	.65	163.82
Oregon	839,988	5,508	488,672	.58	88.72
Pennsylvania	4,607,853	26,330	2,362,512	.51	89.73
Puerto Rico	---	18,858	1,425,730	---	75.60
Rhode Island	375,389	1,502	245,605	.65	163.52
South Carolina	1,172,901	6,231	1,124,066	.96	180.40
South Dakota	289,755	2,484	244,976	.85	98.62
Tennessee	1,610,268	12,954	1,301,283	.81	100.45
Texas	4,823,151	12,879	2,534,044	.53	196.76
Utah	509,450	2,706	300,134	.59	110.91
Vermont	191,521	2,803	228,794	1.19	81.62
Virgin Islands	---	4,167	103,355	---	24.80
Virginia	1,949,470	17,789	1,358,741	.70	76.38
Washington	1,412,089	4,501	690,361	.49	153.38
West Virginia	702,310	8,430	687,691	.98	81.58
Wisconsin	1,893,221	5,476	1,050,746	.56	191.88
Wyoming	142,345	1,459	176,594	1.24	121.04

SOURCES: Column 2--U.S. Department of Commerce, Bureau of Census, *Number of Inhabitants: United States Survey*, PC(1)-A1, December 1971, p. vii, "Resident Population." Column 3--U.S. Department of Health, Education and Welfare, *Children Who Received Physician's Services Under the Crippled Children's Program, FY 1970*, MCHS Statistical Series No. 3, December 1970, Table 7. Column 4--Senate Hearings, Departments of Labor and Health, Education, and Welfare and Related Agencies Appropriations, Committee on Appropriations, 92nd Congress, First Sess., pp. 3369-3370, Columns 5 and 6, derived.

calculations) as well as to differences in the kinds and numbers of various disorders served, to the amount of service given to each individual, and to local market considerations for health services. On a state-by-state basis, it is extremely hard to believe that per capita or per client CCS expenditures are equitable.

CURRENT MEDICAID PROGRAM

Under Title XIX of the Social Security Act, as amended, medical payments are being made to some indeterminate number of handicapped children from financially needy families. Fiscal Year 1971 Federal expenditures were \$3,373,865,665.¹⁴ The total payments for vendor medical bills under the Title XIX program, including the state contribution, were \$5,939,236,000 in Fiscal Year 1971.¹⁵ We note that this program is in a stage of rapid growth. Understanding of Medicaid is complicated to a considerable extent by the diversity of programs that the states offer.¹⁶ The Federal contribution in Medicaid varies from 50 to 83 percent based on a state's per capita income. While coverage must be given to all persons receiving income maintenance under the Social Security Act and children under 21 in families must be covered, the states may also cover "medically needy" persons who require financial assistance with medical bills but do not need income maintenance in general.¹⁷

Number Receiving Medicaid

An estimated 8,300,000 different children under age 21 received assistance under Title XIX in the category of Medical Assistance in FY 1971.¹⁴ We are unable to determine just what proportion of these totals is handicapped because information on the child's medical condition, i.e., the kind, extent, and degree of handicap, is not compiled from the individual's case files into basic state reports. Also, the transitory receipt of medical services makes accounting for who is in the program receiving what kinds of services at any one point in time an extremely difficult undertaking.

The midmonth quarterly summary, presented in Tables 8.22 and 8.23 for May 1971, contains one source of information on Title XIX expenditure and service rates.¹⁸ The tables show that both handicapped and nonhandicapped youth represented at least 35.2 percent of the total Title XIX caseload, and that they accounted

¹⁴ U.S. Congress, House, Hearings before a Subcommittee of the Committee on Appropriations, *Departments of Labor and Health, Education and Welfare Appropriations for 1973—Part 5*, 92d Cong., 2d Sess., p. 316.

¹⁵ U.S. Department of Health, Education and Welfare, *Trend Report, Social and Rehabilitation Service*, DHEW Publication No. (SRS) 73-03101, October 6, 1972.

¹⁶ U.S. Department of Health, Education and Welfare, *Characteristics of State Medical Assistance Programs Under Title XIX of the Social Security Act*, 1970 ed. For example, only 17 states covered all financially needy individuals under age 21 in 1970.

¹⁷ U.S. Congress, House, Hearings, loc. cit., p. 317. The 1972 amendments to the Social Security Act provided for Medicare protection to persons who have received Social Security disability benefits for at least two years. This provision will not only benefit disabled adults, but also disabled youth. The Social Security Administration will also assume responsibility for determining eligibility for Medicaid in conjunction with Supplemental Security Income disability determinations.

¹⁸ U.S. Department of Health, Education and Welfare, *Medical Assistance (Medicaid) Financed under Title XIX of the Social Security Act*, Social and Rehabilitation Service, DHEW Publication No. SRS 72-03150, October 27, 1971.

Table 8.22

RECIPIENTS OF MEDICAL ASSISTANCE: BY BASIS OF ELIGIBILITY, FORM OF MEDICAL ASSISTANCE,
AND MONEY PAYMENT STATUS, MAY 1971

Basis of Recipient Eligibility	Recipients of Medical Assistance					
	Total	For Whom Payment Made to Vendors Directly or Through Fiscal Agent		For Whom Other Premium or Per Capita Payments Made ^a		
Number of Recipients						
Age 65 or over	2,519,000		1,733,000		1,912,000	
Blindness	51,200		47,200		17,600	
Permanent and total disability	744,000		731,000		39,400	
Membership in family with dependent children under 21, total	3,693,000		3,521,000		217,000	
Adults ^b		1,311,000		1,282,000		42,900
Children ^b		2,202,000		2,080,000		136,000
Other Title XIX recipients, total	509,000		505,000		3,800	
Age 21-64 ^b		159,000		158,000		1,100
Under age 21 ^b		291,000		288,000		2,700
Total recipients	7,513,000		6,535,000		2,190,000	
Percent Distribution of Recipients						
Age 65 or over	33.5		26.5		87.3	
Blindness	0.7		0.7		0.8	
Permanent and total disability	9.9		11.2		1.8	
Membership in family with dependent children under 21, total	49.2		53.9		9.9	
Adults		18.4		20.6		2.4
Children		30.8		33.3		7.5
Other Title XIX recipients, total	6.8		7.7		0.2	
Age 21-64		2.4		2.7		0.1
Under age 21		4.4		5.0		0.1
Total recipients	100.0		100.0		100.0	

NOTE: Data represent totals of rounded state data. Totals may not equal sum of parts.

^a Made into agency pooled fund, into Social Security Administration system or into health insurance agency.

^b Data incomplete.

Table 8.23

AMOUNT OF MEDICAL ASSISTANCE: BY BASIS OF ELIGIBILITY, FORM OF PAYMENTS,
AND MONEY PAYMENT STATUS, MAY 1971

Basis of Recipient Eligibility	Total	Payment Made to Vendors Directly or Through Fiscal Agent	Other Premium or Per Capita Payments ^a
Amount of Payments			
Age 65 or over	\$227,994,000	\$215,541,000	\$12,448,000
Blindness	4,013,000	3,915,000	96,100
Permanent and total disability	119,556,000	119,344,000	213,000
Membership in family with dependent children under 21, total	189,978,000	189,071,000	906,000
Other Title XIX recipients, total	41,183,000	41,162,000	20,900
Age 21-64 ^b	\$18,994,000	\$18,988,000	\$ 5,700
Under age 21 ^b	16,061,000	16,046,000	15,200
Total payments	\$582,724,000	\$569,036,000	\$13,687,000
Percent Distribution of Payments			
Age 65 or over	39.1	37.9	90.9
Blindness	0.7	0.7	0.7
Permanent and total disability	20.5	21.0	1.6
Membership in family with dependent children under 21, total	32.6 ^d	33.2	6.6
Other Title XIX recipients, total	7.1	7.2	0.2
Age 21-64	3.8	3.9	(c)
Under age 21	3.3	3.3	0.1
Total payments	100.0	100.0	100.0

NOTE: Data represent totals of rounded state data. Totals may not equal sum of parts.

^aMade into agency pooled fund, into Social Security Administration system or into health insurance agency.

^bData incomplete.

^cLess than 0.05 percent.

^d12.2 percent for adults and 20.4 percent for children, assuming payments are proportional to number of recipients.

for at least 23.7 percent of expenditures in May 1971, or about \$138 million of the total \$582.7 million. Also note that 87 percent of the children were from AFDC families. Lacking better data, we estimate that the number of handicapped children served by Medicaid is the same as the proportion of the U.S. population under age 22 who are handicapped.¹⁹

We also assume, for lack of better data, that the expenditure per handicapped child is the same as that for all children in the Medicaid program. Thus we estimate that in FY 1971 Medicaid served 1,097,000 handicapped children at a cost to the Federal Government of \$105,548,000. Including costs to the states, the total is an estimated \$185,803,000. Because handicapped youth in general need more medical services than normal youth, we view these estimates as the minimum amount of resources the program is using to serve the handicapped.

Table 8.24 gives the per inhabitant expenditure rate for medical assistance under Title XIX.

Federal-Level Program Assessments

Interviews were conducted with officials in the responsible Federal agencies (Medical Service Administration and Assistance Payments Administration of the Social and Rehabilitation Services), state agencies, and local agencies. What the most senior personnel in the Assistance Payments Administration had to say about Medicaid seems worth summary comment.²⁰ One interesting observation had to do with the "last resort" nature of the Title XIX caseload. It was surmised that many handicapped children who find their way into the program have simply been "missed" by other agencies or by physicians who are not aware of alternative programs such as the Crippled Children's Service program. In some cases, however, the Medicaid program is the "only resort." The needs for individual level diagnosis and direction were stressed.

It was indicated that the states have so much diversity in the kinds of services provided, definitions of eligibility, and accounting systems used that it is practically impossible to sort out and keep track of the caseload. Most agreed that the delivery of this type of service should be done at the local and individual level; however, the accounting and evaluation aspects of this program were weak but are improved greatly by a newly designed Medicaid Management Information System that states can adopt.

Rarely do records of health services rendered accompany the child when he goes for services under Title XIX. Furthermore, it was asserted that these records are seldom obtained; rather a completely new medical record work-up on each child is instituted. While we cannot estimate the costs involved with redundant rediagnosis and recertification, the existence of such apparently common practices is not in the best interests of either the child or the efficient execution of the services.

Federal officials were especially pleased that the 1967 Amendments providing for early and periodic screening, diagnosis, and treatment of Medicaid-eligible children be made a required aspect of Title XIX programs. However, compliance and

¹⁹ For data sources on incidence rates in the general U.S. population, see Appendix A.

²⁰ Interview, Assistant Payments Administration, U.S. Department of Health, Education and Welfare, March 14, 1972.

Table 8.24

AMOUNT EXPENDED PER INHABITANT^a FOR MEDICAL ASSISTANCE,^b BY BASIS OF ELIGIBILITY,^c FY 1971

State	Total	Adult Programs	AFDC		Other
			Amount	Percent of Total	
U.S. average ^d	\$29.20	\$17.45	\$ 9.75	33.4	\$ 2.00
Alabama	25.15	17.55	7.55	30.1	.05
Arkansas	6.40	4.60	1.75	27.5	.05
California	51.65	30.95	20.15	39.0	.55
Colorado	23.40	18.10	5.25	22.4	.05
Connecticut	30.30	21.90	6.90	22.7	1.50
Delaware	11.35	3.80	7.35	64.9	.20
D.C.	49.60	15.50	26.50	53.4	7.60
Florida	11.65	8.20	3.45	29.7	---
Georgia	27.25	20.05	7.20	26.4	---
Guam	4.90	(e)	(e)	---	(e)
Hawaii	22.95	10.45	8.30	36.2	4.20
Idaho	14.20	9.30	4.90	34.4	---
Illinois	24.35	14.90	9.30	38.1	.15
Indiana	9.00	6.75	2.25	24.8	---
Iowa	8.55	3.40	5.10	59.6	.05
Kansas	16.80	6.90	6.50	38.8	3.40
Kentucky	20.75	12.75	7.90	38.0	.10
Louisiana	14.55	10.75	3.80	26.0	---
Maine	17.15	9.00	7.70	45.0	.45
Maryland	28.05	14.80	8.75	31.2	4.50
Massachusetts	53.60	38.65	10.50	19.6	4.45
Michigan	29.45	18.60	9.80	33.3	1.05
Minnesota	28.65	19.70	7.10	24.8	1.85
Mississippi	15.85	14.05	1.80	11.4	.02
Missouri	12.65	8.40	3.25	25.7	1.00
Montana	15.15	9.40	5.75	37.8	---
Nebraska	14.75	9.75	5.00	34.0	---
Nevada	14.90	8.55	6.10	41.1	.25
New Hampshire	9.55	5.05	4.25	44.5	.25
New Jersey	22.30	12.80	9.25	41.4	.25
New Mexico	15.65	7.55	7.95	50.9	.15
New York	80.65	43.10	26.35	32.7	11.20
North Carolina	18.25	12.85	5.40	29.5	---
North Dakota	20.90	15.85	4.65	22.3	.40
Ohio	12.05	7.55	4.50	37.4	---
Oklahoma	37.30	21.15	9.45	25.3	6.70
Oregon	9.40	3.85	5.30	56.6	.25
Pennsylvania	29.80	12.85	11.15	37.4	5.80
Puerto Rico	16.75	2.05	11.05	66.0	3.65
Rhode Island	42.65	30.55	11.80	27.7	.30
South Carolina	12.65	10.15	2.35	18.6	.15
South Dakota	13.40	10.20	3.20	23.9	---
Tennessee	8.95	5.70	3.25	36.3	---
Texas	15.55	10.35	5.20	33.3	---
Utah	15.35	8.15	6.25	40.8	.95
Vermont	31.75	19.75	10.75	33.9	1.25
Virgin Islands	16.30	3.70	5.15	31.6	7.45
Virginia	10.80	5.90	4.35	40.1	.55
Washington	29.80	18.90	7.75	26.0	3.15
West Virginia	11.45	4.30	6.40	56.0	.75
Wisconsin	35.15	24.30	7.70	21.9	3.15
Wyoming	5.05	3.05	2.00	39.2	.02

SOURCE: U.S. Department of Health, Education and Welfare, *Trends Report, Social and Rehabilitation Service*, DHEW Publication No. (SRS) 73-03101, October 6, 1972.

^aBased on resident population as of July 1, 1971, excluding armed forces overseas, estimated by the Bureau of the Census.

^bExcludes general assistance.

^cDistribution by basis of eligibility estimated.

^dAlaska and Arizona have no program.

^eData not available.

full implementation of these provisions have been hard to attain from the states. Data accounting for total numbers of individuals screened, referral rates, disease incidence, and follow-up measures undertaken are beginning to be collected, but the results are incomplete. To the basic question, "How many children were screened under this program?" asked by the Medical Services Administration of SRS in January 1973, 26 states either did not reply or did not have implemented programs. Data on disease incidence were even more fragmentary and incomplete. Data on follow-ups will be available in late 1973, but will only report on "the degree of follow-up at two or three screening sites in each of seven States."²¹

State Interviews

The general themes mentioned in the above paragraphs are repeated in our state interviews. In Illinois we were told that it was impossible to determine the number of handicapped children in the caseload.²² When data are collected, they are not used at the state level for operational purposes, but "only to satisfy Federal requirements."²³ Children often "fall between the cracks" under Title XIX because of the categorical clause in the eligibility requirements, and "with a fully employed father, the child cannot get medical assistance, even though the father is making a pittance and the bills are piling up."²⁴ In this same interview, the categorical restriction was found to be constraining.²⁵ It was constraining not only for the children but for the doctors for whom the "reasonable, usual, and customary fees" did not make much economic sense, and for whom the red tape and long delays in getting paid made even less sense. It was also felt (although the question is an open, empirical one) that follow-up on children identified by screening programs was low. In the other states we visited, the messages were about the same.

OTHER PUBLIC HEALTH PROGRAMS

A number of other health-related programs have been identified and must have some impact on handicapped children. Although their impact is extremely difficult to assess, we note them nonetheless.

Comprehensive Health Care and Communicable Diseases

Three separate programs are known to emphasize comprehensive health care and the improvement of prevention services, both relevant to handicapped children. These are Communicable Disease Prevention and Control, Health Services Develop-

²¹ Correspondence, Early and Periodic Screening Diagnosis and Treatment Program, Medical Services Administration, July 31, 1973. Signed by M. F. Abdalla, Program Analyst, Office of Program Planning and Evaluation. Data provided from same source.

²² Interview, Illinois Children and Family Assistance, September 27, 1972.

²³ Interview, Division of Medical Services, Division of Public Aid, Illinois, September 29, 1972.

²⁴ Ibid.

²⁵ Ibid.

ment—Project Grants, and Comprehensive Public Health Services—Formula Grants and Migrant Health Grants.

Communicable Disease Prevention and Control.²⁶ Headquartered in Atlanta in the Epidemiology Program of the Communicable Diseases Center, this program is responsible for national surveillance activities that included in 1971 reports on hepatitis, salmonellosis, influenza, and diphtheria. Besides direct observation, the FY 1972 expenditure of some \$1.709 million provided for consultation, technical assistance, and training for each of the state health agencies.

Communicable Disease Control is also funded under Section 317 of the basic Public Health Service Act, and some proportion of the \$7.213 million of FY 1971 expenditures for a variety of immunization activities impacted on children.²⁷

Health Services Development—Project Grants.²⁸ The concept of developing comprehensive health services at the local level has been embodied in this particular program. New projects are developed and initially supported, some training is done, and priority has recently been given to constructing comprehensive health centers. Project grants are made to the states directly by the Division of Health Care Services of the Community Health Care Service in Health Services and Mental Health Administration. In FY 1971 about \$108 million was awarded in support of 43 comprehensive health service projects, including \$30 million for 16 neighborhood health centers. Other projects funded in FY 1970 included \$16 million for rubella immunization; \$19.3 million for 27 comprehensive health service programs; \$12.8 million for rat control; and \$25.5 million for chronic disease programs.²⁹ Certainly some of these resources benefited handicapped children, but estimating just what proportion that might be is difficult. The rubella prevention program is the only one primarily and directly aimed at the problem of preventing handicapping conditions. For women contracting rubella in their first trimester of pregnancy, the chances of giving birth to a handicapped child are high: about a 15 percent chance of visual impairment; a 20 percent chance of hearing impairment; a 5 percent chance of both deafness and blindness; and a 5 percent chance of mental retardation or orthopedic impairment.³⁰

Comprehensive Public Health Services—Formula Grants.³¹ A related program monitored by the Office of Program Planning and Analysis of the Community Health Service granted on the order of \$90 million in FY 1971 to the states for a wide variety of innovative and developmental services. The program gave some preference to services for "high risk" populations, including the poor. It is impossible to determine what fraction of the basic line goes to handicapped children, although some of it obviously does.

Migrant Health Grants.³² The Division of Health Care Services of Community Health Services, HSMHA, is also responsible for improving the "health

²⁶ Public Health Services Act, amended, sections 301, 311, 315, and 361-69.

²⁷ Additionally, some \$16 million was expended for venereal disease control under provisions of this program. *Catalog of Federal Domestic Assistance, Update*, Office of Manpower and Budget, November 1972, p. 186.1.

²⁸ PHS, Title III, Section 314(e), amended; P.L. 89-749; P.L. 90-174; and P.L. 91-515.

²⁹ *Catalog of Federal Domestic Assistance*, p. 156.

³⁰ D. E. Hicks, "Comparison Profiles of Rubella and Non-rubella Deaf Children," *American Annals of the Deaf*, Vol. 115, pp. 86-92, March 1970. See also, D. Calvert, *Report on Rubella and Handicapped Children*, U.S. Department of Health, Education and Welfare, May 1969, pp. 1-6.

³¹ PHS Act, Title III, Section 314(d), amended.

³² P.L. 90-574, P.L. 91-209, and 42 U.S.C. 242h.

status of migratory seasonal workers and their families to that of the general population."³³ Some proportion of the FY 1971 expenditures of about \$14.0 million benefited the children of migratory workers through organized family health clinics. How many of those children are handicapped or how many handicapping conditions were prevented as a result of those services is not known.

Construction

The so-called "Hill-Burton Program"³⁴ is one of the largest single Federal sources of construction funds and has had as its stated objective the provision of hospitals, public health centers, laboratories, outpatient facilities, emergency rooms, neighborhood health centers, long-term care centers, rehabilitation facilities, and related health facilities. It has been, in effect, the omnibus hospital construction legislation. In this role, in FY 1971, some 450 separate projects providing around 10,000 new or modernized beds at a cost of \$172 million were undertaken. Handicapped children benefited certainly, but there is little reasonable basis for estimating what fraction of Hill-Burton money is directly attributable to this class of individuals.

Dental Health ³⁵

A 1969 amendment to the Social Security Act was designed to promote the dental health of preschool and school-aged children, particularly in low income areas; \$860,000 in grants were made to the state health departments in FY 1972. The program has been in operation only two or three years and has stressed prevention and identification of dental conditions. Some training of paraprofessional personnel has been undertaken, and funds for direct service (i.e. treatment) have also been made available.

Veterans Administration

We were interested in the Veterans Administration as a source of information on the development, testing, and provision of prosthetic devices, and hence paid them a visit. We learned that the VA also runs a program for handicapped children of veterans. Chapter 35 of the basic enabling legislation provides "Restorative Training" for the wives, widows, and dependents of those who have suffered service-connected disabilities.³⁶ It is especially Part 5 of Chapter 35 that allows the VA to aid damaged, handicapped, and congenitally malformed children.

The VA has commendable provisions to inform these children that they might have services provided. When the eligible child reaches age 13 a letter is sent to the parent or guardian informing him of the benefits available under the code. The

³³ *Catalog of Federal Domestic Assistance*, p. 173.

³⁴ PHS Act, Title VI; P.L. 88-443 and P.L. 91-296.

³⁵ Social Security Act, amended, Title V, Section 510; P.L. 90-248. *Health and Services for Mothers and Children Under Title V, Social Security Act*, 1969.

³⁶ Title 38 U.S.C., Chapters 31, 34, 35, and 36 are the relevant pieces of legislation that have enabled the VA to serve handicapped children. See particularly Chapter 35.

Veterans Administration Regional Offices serve as the points of contact and provide diagnostic and rehabilitation services in the main. "Damaged" children begin receiving benefits at age 14, and it was "estimated" by officials in the VA's Rehabilitation and Educational Services Division that some 200,000 children had received or were presently receiving such services.³⁷ The program is designed to diagnose and then rehabilitate the child; occupational objectives are foremost in the program.

In interviews with officials of the Prosthetics and Sensory Aids Division of the VA, we learned that eligible children were receiving audiological diagnoses in some 35 clinics spread over the country and that hearing aids were being fitted and evaluated if needed. We also learned that services for blind, eligible children were primarily given through three VA Hospitals (Palo Alto, New Haven, and Hines-Chicago), and that prosthetics are available from some 20 specialized centers throughout the country.³⁸ It is even more problematic to assess the benefits that have accrued to handicapped children as a result of the large-scale prosthetics research, development and implementation program run by the VA, although there is no doubt that some such impact exists.

We were unable to obtain any detailed population data on these children beyond the approximation of the total number who were receiving services of all varieties. Nor could we obtain any specific cost breakdowns.

The program that the Veterans Administration is running for handicapped children is very special; its existence is not widely known and the integration of its impact on the total needs of the handicapped population at large is extremely hard to assess.

Department of Defense

Under provisions of P.L. 89-614, September 1966, the "Dependent's Medical Care Act," health care benefits for dependents of servicemen are provided if they are severely mentally retarded or have a serious physical handicap. According to a deductible schedule based on the service member's rank and pay, the law provides for up to \$350 per month for diagnosis, inpatient, outpatient and home treatment, training, rehabilitation, and special education, institutional care in public and private nonprofit institutions, and transportation to and from these facilities. The program is small compared with the mainline agencies and programs that we concentrate on, but it is indicative of the fragmentation that exists among divisions of the Federal Government. An on-going and proper accounting of children served under this and other highly specialized programs is clearly a Federal task, but no one has yet taken up the task of collecting the data centrally or in any way that would lend itself to analysis and programmatic evaluation.

Department of Interior/Department of Health, Education and Welfare

The Bureau of Indian Affairs of the Department of Interior transferred its responsibility for providing health services to the Indian Health Service in Health

³⁷ Interview, Division of Rehabilitation and Educational Services, Veterans Administration, August 8, 1972.

³⁸ Interview, Division of Prosthetic and Sensory Aids, Veterans Administration, August 9, 1972. Work includes the evaluation of laser cane systems and reading devices for the blind as well as hardware for orthopedic handicaps.

Services and Mental Health Administration of DHEW.³⁹ The program provides some 51 Public Health Service Indian Hospitals, 79 health centers and school health centers, over 300 other health stations, and contracts for services arrangements with private and community hospitals. Eligibility is extended to the nearly one-half million "American Indian and Alaska Natives," as determined by proximity to a reservation or by community recognition and self-identification as "Indian." Some proportion of the FY 1972 total expenditure of \$154 million⁴⁰ benefits handicapped Indian children, but we made no effort to measure this exactly and merely note the existence of yet another program benefiting a special category of handicapped children.

STATE CRIPPLED CHILDREN'S SERVICE AND PUBLIC HEALTH AGENCY SURVEY RESPONSES

The survey responses from Crippled Children's Services in the states were excellent, mainly because it is a single, coordinated program which maintains reasonably good data. We collected responses from Departments of Public Health to elicit opinions about other Maternal and Child Health Programs, but the results of that inquiry are inconclusive and noncomparable; in effect, one must look at each state separately and make assessments accordingly.

Problem Areas Noted by State CCS Program Administrators

Funding, or the lack of it, in the face of increasing caseloads and rising medical costs, is the foremost problem cited in response to the questionnaire survey. The replies from the questionnaire, summarized in Table 8.25, support the general points on this subject made previously. It should be noted that replies on problems with the CCS program were voluntary in response to an open-ended question in the survey, and hence the representativeness and completeness of responses is open to some question. It is nonetheless useful and important to take these cited problems into account in making a more general assessment of CCS. Specific comments illustrate the main points in Table 8.25.

Funding. "Traditionally this program has been inadequately funded and has run out of funds by the time the fiscal year was half over," reported New Mexico. "The reduction in funds has meant that applications have been reduced by 27 percent this year," and it has meant for South Carolina that "only applications for persons in acute financial and medical need were solicited and accepted." On the issue of coverage and available funds in Tennessee it was noted, "The finances available to the Service are limited. Since the definition of a crippled child is so broad, it sometimes becomes necessary to limit the program to certain diagnoses in order to stay within available funds." And a final, representative, summary comment from West Virginia: "In recent years . . . we have been faced with the problem of attempting to provide services to a very rapidly increasing caseload with just as

³⁹ 42 U.S.C. 2001-2004a.

⁴⁰ *Catalog of Federal Domestic Assistance*, p. 157.

Table 8.25

PROBLEMS CITED IN SURVEY RESPONSES BY CCS PROGRAM ADMINISTRATORS

	FUNDS					PROGRAMS/PERFORMANCE					MISCELLANEOUS			
	Need Increased Federal Funding	Federal Share Inadequate	Need Personnel Increase	Insufficient Funds to Serve Catastrophic Diseases	Unstable Funding/Late Funding	Improve Federal Guidelines-- Better Minimal Service Coverage	Not Reaching All Who Are Eligible	Too Many Changes in Federal Guidelines	"Political Pressures"	Lack of Coordination (Federal, State, & Local)	Poor Accountability/Data/Evaluation	Insufficient Specialists	Need Better Medical Diagnosis & Assessment	Geography--Transportation to Services
23 States Responding ^a														
California	●	●												
Colorado	●					●								
Florida			●				●							
Georgia	●													
Idaho									●			●		
Illinois	●			●			●							
Iowa				●				●						
Kansas			●						●	●	●		●	
Minnesota	●		●						●					
Missouri	●		●			●	●	●	●	●				
Nevada	●		●			●	●		●	●				
New Mexico	●	●	●			●	●		●	●	●		●	
New York	●			●					●	●				
North Carolina ..							●		●	●				
North Dakota									●	●				
Ohio	●	●						●	●	●	●			
Pennsylvania	●								●	●				
South Carolina ..	●					●			●	●	●		●	
Tennessee	●					●			●	●				
Virginia	●					●			●	●				
Washington	●					●	●		●	●	●			
West Virginia ...	●					●			●	●				
Wyoming	●					●							●	
Total	16	3	6	1	2	9	6	2	5	9	6	5	1	4
Total	28					37					10			

^aThe following 15 states responded to questionnaire, but did not voluntarily answer questions on problems: Alabama, Alaska, Connecticut, Hawaii, Indiana, Kentucky, Maine, Michigan, Montana, Nebraska, New Jersey, Oklahoma, Oregon, Texas, and Wisconsin. The following 11 states did not respond to the questionnaire: Arizona, Arkansas, Delaware, D.C., Louisiana, Maryland, Mississippi, New Hampshire, South Dakota, Utah, and Vermont.

rapidly increasing medical costs . . . we do not feel the funding was increased sufficiently to handle the broadening of the Program and expansion of services."

On Stability of Funding and Results. From Iowa: "Late knowledge of funding makes planning and operations very difficult." New York State feels the need to stabilize the method of funding. In addition, allowance must be made for providing a mechanism which provides for rising costs and improvements in technology which affect costs.

Personnel Increase. From Florida the need of more personnel to insure adequate coverage is noted in the following terms, "If a full range of services were to be provided to all citizens who need it, we would have to have more personnel and resources." Minnesota's respondent stressed that they would like to "strengthen follow-up care in the community through increased staffing."

Programs and Performance. As a collective class of specific problems, programs and performance accounted for the bulk of the complaints, although many of the problems are clearly rooted in insufficient resources. Noted most frequently were problems with the Federal guidelines, particularly who should be served, and the lack of coordination between Federal and state levels of authority and responsibility among related local programs. The issue of who to serve is a profoundly difficult one having deep moral implications, and is not uniformly resolved by the states. Depending on the time of the fiscal year, the number of children who are currently in the queue awaiting services, and the specific selection mechanisms that the individual state has worked out to make these choices, enormous disparity exists (from state to state and within a single state at different times) between the classes and numbers of children who will be served.

Guidelines and Eligibility/Coverage. Nevada has insufficient funding "to provide and include the following conditions in the CCS program: neoplasms, endocrine and metabolic diseases, blood dyscrasias, hyaline membrane disease, severe skin conditions, cystic fibrosis, and convulsive disorders." What happens to children suffering from these disorders in Nevada was not mentioned. In Washington State, "CCS provides medical care through the autonomous county and District Health Departments. No funding is available to them directly for the nursing, consultative, and clinical services provided." In South Carolina the moral dilemma was underscored when funds ran out, as was the case in 1971-1972 when hospitalization was "curtailed" for 4.5 months and "Many children needing hospitalization during this curtailment period were unable to receive such care."

Coordination. On the issue of coordination, one striking feature is that the states who listed this as a problem are also the ones that have attempted to do something about it by creating "agreements" among related service providing agencies either by collapsing all resources as much as possible into a common "kitty" from the CCS, MCHS, and Title XIX programs or by creating handicapped registers and other information and accounting systems.

Iowa's CCS agency indicated, "Without a Federal coordinating council, it is not easy to create state coordinating councils. The result is that some services are reduplicated and some are not provided." Pennsylvania is trying to rationalize all programs for the handicapped and recommends "Merger of all Federal funding for medical problems of children into one agency, with sufficient capacity to conduct cost analysis and impact evaluation of programs." To these ends, the Governor of Pennsylvania is to be commended for creating a Commonwealth Child Development

Committee.⁴¹ In West Virginia the problem has reached the point where it is noted, "There is great need for concentration of effort and cooperation of agencies and programs to conserve medical manpower, better utilization of manpower and facilities, resulting in improved services to the handicapped"; the problem is defined as being largely federally created and results in "duplication of effort caused by new legislation providing funding in various directions."

Poor accountability was noted in several responses and revolves around the problem of inadequate standards and procedures of data collection and analysis. It is an issue of some moment, given the current debate about special revenue sharing and the need for evaluation control.

Accountability. The Missouri survey response indicated that "There is a great need to reevaluate Federal statistical reports—outdated; also some reports are a nightmare to read and interpret." Pennsylvania's response pointed out that "The cost-effectiveness of various programs is really not known. By and large, criteria to evaluate the effect of public supported services on the lives of the handicapped are not available."

And finally, one comment from Ohio captures the essence of the several notices about the "political pressures" operating in the program; it also serves admirably as a summary statement for this brief excursion into the survey responses on the problems with the CCS program. " 'Splintering' at service level must be stopped. It occurs because Congress adopts funding for specific disabilities. There should be a coordinated contribution by the Federal and state governments, and states should have coordinated programs for 'handicapped youth'."

Notable Features of Selected CCS State Programs

We point out in Table 8.26 some notable program features that are worth more detailed investigation in subsequent, in-depth investigations of the CCS program. Several points are worth elaboration. Illinois and Oregon have located their Crippled Children's program within the organizational superstructure of a state university, and in both cases the results appear favorable. Several other states have made good to excellent use of the research and medical care facilities of university medical centers, and we would list Iowa and Minnesota as two representative examples of this practice.

Program analysis of reasonably high quality, as evidenced by the detailed and competently executed samples of work returned with the survey questionnaire, is being done in Indiana, New York, Pennsylvania, Colorado, Washington, and several other states. Future investigations of CCS (particularly if revenue sharing becomes a reality) should determine what it is about the evaluation and analysis functions in each of these states that makes them stand out from the average. Then efforts should be made to try to replicate those positive features in as many other states as possible.

Why does Colorado have a total registry for the handicapped, and what do they do with the information contained in it? Are services more effectively provided in Indiana because they have a detailed health-service index that allows some fairly sophisticated analysis to support and precede the hard choices about who should be

⁴¹ Governor of Pennsylvania, *Executive Directive #35*, March 30, 1972.

Table 8.26

SOME NOTABLE FEATURES OF SELECTED STATE CCS PROGRAMS

State	Features
Alabama	Relies exclusively on physician referrals
California	Depends on the medical (Medicaid) program for 50 percent of CCS support
Colorado	Maintains Registry of Handicapped Children; good accounting and planning evident
Connecticut	CCS folded in with Department of Public Health
Illinois	Good records; good accountability for individual children in case load; university based
Indiana	Good program analysis group; thorough plan
Iowa	Good use of state university; lively and imaginative research component; strong identification component
Michigan	Coordinated plan, combination of CCS/MCHS/Title XIX resources under one administrative umbrella; Register of Handicapped by county
Minnesota	Thorough, comprehensive plan; strong outreach (identification) component; proud of medical diagnosis activities
Nevada	Concise handbook detailing CCS for participating physicians
New York	Good plan based on demographic forecasts; clear statement of CCS objectives; well-specified list of approved disorders
North Carolina	Central billing service for MCHS, CCS, and Chronic Diseases (reduced administrative overheads)
Oregon	University based; good research component
Pennsylvania	Integration and coordination of MCHS and CCS to get more care for available resources; good plan
South Carolina	Child Evaluation Clinics--diagnosis, direction, and resources planning for individual child
Washington	Good management information system support utilized; coordination "agreement" between Public Assistance and CCS/DPH; good plan; good use evident of University of Washington for research
West Virginia	CCS in Department of Welfare resulting in coordination of CCS and Title XIX resources and programs
Wisconsin	Thorough financial eligibility statements and procedures
Wyoming	Detailed plan; mobile teams to serve remote areas

served, for how long, and with how many resources? If such is the case, and we have a strong suspicion that it is, then what might Federal officials do to promulgate the analytic lessons that have been learned the hard way in Indiana so that all states might benefit? We have already seen that Minnesota is identifying and serving nearly four times as many multiply handicapped children as the national average, why? Can whatever Minnesota is doing be replicated elsewhere to improve the identification, diagnosis, and planning for services needed by multiply handicapped children throughout the country? If the answer is "yes," then Federal officials might take some responsibility to see that what Minnesota and other states are doing "right" for their children begins to be done "right" for children in all states.

Summary Comments from In-Person State Interviews and Survey: CCS Program

The following are general summary comments made to us about the CCS program:

- The level of funding has remained relatively stable in absolute dollar terms over the past five years or so, has not kept pace with inflation generally, or with the hyper-inflation of the medical market, and has resulted in reduced coverage and aggravated the serious ethical issue of selecting which handicapped children to serve.
- The national policy for the Crippled Children's Program is not clear; indeed the state-to-state variability in the number of dollars devoted to differing numbers of children having vastly different mixes of handicapping conditions is staggering.
- CCS is not reaching even half of those who in all likelihood could benefit from it and are entitled to the services it represents.
- With several noted exceptions, individual children are not tracked to assure a good match between the specific services required and the specific and changing needs of the handicapped child.
- Categorical coverage of specific diseases has been resorted to both in response to Federal legislative pressure and to the need to make choices about which classes of disease should be covered with limited funds. The result has been "faddish" and capricious cycles in covered diseases (where a child with disability X in one state receives coverage, and a child in an adjacent state having the same problems and an equally legitimate claim to services does not).
- With several notable exceptions, planning and resource guidance information for the families of CCS recipients is not well developed, and should be. It is expecting too much of the parents of a handicapped child to know which specialist is best to treat their own child and where to get the resources (in addition to CCS support) to which they are entitled and which might make the difference between proper and inadequate care. This function, given the fact that the market for this kind of information is imperfect at best, is readily performed by states and localities, but only if some uniform demand for it is placed on them, and that is a potential Federal job.
- The CCS model is general purpose (or has become so with the addition of a variety of handicapping conditions in the last ten years), well-run for the most part, and probably should be considered for expansion and emulation. If other mechanisms of assistance are not working and are collapsed or terminated, it was suggested that the CCS delivery mechanism be considered as a viable, well-tested alternative.

Problem Areas Noted by State Public Health Administrators. Of those administrators completing the questionnaire, most did little more than present a sample of the programs that they thought benefited handicapped children; very few made any comments about problems or suggested ways the system might be improved. Officials in ten states responded with specific comments about problems and suggestions for improvement; an additional fifteen responded but did not volunteer any comments.

Of the ten responses with suggestions, noted were the need for coordination of services and less fragmentation of programs. For instance, from Illinois we heard, "MCH, Title XIX, and CCS are all competing for the same kids, but they [the programs] are a mess to understand and figure out." In Oklahoma, the problem of categorical programs was noted as well as the coordination issue: "There are just too many categories; we need a 'Civil Rights for the Handicapped' to treat them just like other people."

Eight state administrators wrote that they would like to comply with our request to fill out the questionnaire but for a variety of reasons they could not (i.e., staff problems, lack of data, too many other questionnaires).

Interviews with Public Health Administrators. The coordination of services problem was central in the discussions we had with Department of Public Health officials. MCHS programs stress screening for hearing and visual disorders; however, there are implementation problems that are not reported in gross summary statistics. In Illinois, for instance, CCS has a small program for hearing disorders and essentially none for vision; Children and Family Services runs the residential schools for the deaf and blind; Vocational Rehabilitation provides job placement and training services for the visually and aurally impaired over age 16; the Office of the Superintendent of Public Instruction (State Board of Education) is responsible for training and special education and has been responsible for the school nurses who have done screening in the past; and now the Department of Public Health has been reassigned responsibility (largely because of MCHS money) to take over hearing and visual screening. "School nurses are not particularly happy, and fear the loss of their job." The Health Department is not staffed to do the whole job and still depends on schools to screen in the predominantly rural and poor areas; and screening not done by the Department of Public Health directly must be monitored by consultants to insure compliance with standards, but such consultants are hard to get and are expensive. The result is that this one major program—hearing and vision screening—requires an interagency coordination committee, but there is no such committee and the likelihood that there ever will be one is "not high given the vested interests in competing departments."⁴² We strongly suspect that this example is symptomatic of many difficulties resulting from the piecemeal approach characterized in the current provision of health-related services.

Insufficient resources, of course, is noted in many of the interviews as a basic problem with MCHS programs at a state level. In Wyoming, for example, we were told that 11 of the 23 counties do not have full time public health nurses and depend for these services upon itinerant traveling nurses or on welfare case workers. Despite the fact that the Rehabilitation and Health Departments have incentives to cooperate, they both maintain separate pools of medical talent, but cooperate on cases that are unusually expensive. School nurses are autonomous from the Health Department, are paid by the State Education bureaucracy and, with the exception of providing vaccines, Public Health has little or no control over this health (screening, immunization, general care) function.⁴³

The separation of retarded children from regular public health channels was discussed in our interviews in Massachusetts with the comment that in selected

⁴² Interview, Illinois Department of Public Health, September 26, 1972.

⁴³ Interview, Wyoming Department of Public Health, October 11, 1972.

health surveys of the resident retarded population it was discovered that "60 to 70 percent have orthopedic problems, 40 to 50 percent have other medical problems. This means that every child requires two or three speciality medical consultations." It was suggested that they have not routinely been getting all the health services needed. The program to screen children at birth was candidly assessed as "not well done," and other preschool screening efforts were termed "random."⁴⁴

PREVIOUS STUDIES AND DATA AVAILABILITY

Previous Studies

CCS programs have not been assessed in the same detail that, for example, vocational rehabilitation programs have. And the lack of a *strong* research and evaluation component in the basic MCHS program has been noted previously.

Some program analyses have been initiated by the individual states on behalf of their own specific programs or have, rarely, been carried out by ad hoc advisory committees on a nonroutine and not particularly detailed basis. In this latter category, we noted earlier the work of H. W. Wallace et al.,⁴⁵ and would add that while the authors' intentions are well meant, there is little evidence presented in the paper that would allow an interested outside observer to draw his own conclusions about the efficacy of CCS programs. In the state-initiated category, we note the following four interesting but rather specialized and nonaggregated examples.

1. John C. MacQueen and a number of colleagues in Iowa's State Services for Crippled Children conducted a detailed survey of Iowa's handicapped children to determine their precise nature and needs. The survey appears to have been carefully done, is thorough, and policy related as illustrated by this concluding remark:

... the project staff identified one outstanding need shared by all children in the study group—the need for coordination of the complex array of services required by handicapped children and youth.⁴⁶

The report went on to recommend the creation of "Community Service Centers" to cope with this significant, unmet need of all handicapped children. We commend the report to the reader's attention and suggest that it is a viable starting point and design for similar studies in other states. In attempting to measure the number of handicapped children, the severity and degree of their various conditions, the extent and probable duration of their dependency, and immediate and potential needs, the Iowa researchers have essentially gotten to the heart of the largely unresolved and pressing issues of who needs what kinds of services for how long. Stress is given to services that we call "identification" and "direction."

2. Oregon has created a *Policy Manual* that details the CCS program in that state in plain, easy-to-understand language so that a busy physician or a distraught

⁴⁴ Interview, Massachusetts Department of Public Health, August 25, 1972.

⁴⁵ Wallace, Cohen, and Siffert.

⁴⁶ J. C. MacQueen et al., *Planning Comprehensive Services for Handicapped Children and Youth*, Iowa State Services for Crippled Children, Iowa City, Iowa, April 1972, p. 125.

parent might learn quickly and accurately what CCS could do for the handicapped child.⁴⁷ It is a general model that may be worth widespread emulation. We did not determine the extent of this document's distribution throughout the state and hence have no idea of how well it has been received and utilized.

3. The journal, *Tennessee Public Health*, turned over an entire issue to CCS,⁴⁸ but that effort was more descriptive than analytic and was clearly intended to inform the health professionals of Tennessee about the details of the program.

4. Indiana's Division of Crippled Children's Services has created an imaginative *Health Problem Index* that uses the operational data generated in the CCS caseload to develop planning indices; these are used to order in a rational manner the actual problems and potential costs confronting the CCS program in Indiana.⁴⁹ According to this index, accidents, poisoning, and violence (taken as a class) rank first among etiologies demanding CCS attention and responsiveness, diseases of the nervous system and sensory organs are second, diseases of the digestive system are third, and diseases of the bones and organs of movement are fourth. The calculations involved in making this ranking determination are not particularly complex and involve direct consideration of prevalence and lost productivity, among other factors. This sort of initiative could be analyzed by responsible Federal officials and more widespread use encouraged if the results in fact are shown to be improving the quality and management of services.

5. The comments we received from officials in Missouri appear to describe the more normal case of poor or nonexistent program evaluation. In those comments it was noted that there are no good standards for evaluation and hence evaluations are not done or are done differently in different states; there are no good planning standards and hence some states have respectable and useful plans while others have none; and finally, reference was made to the lack of information in feedback from the Federal Government, e.g., a "Federal audit to standardize hospital fee schedules was conducted in Missouri last year, but we never saw the results."

There are literally hundreds of studies that have been conducted on small, well-defined segments of the substantive areas encompassed by MCHS and CCS programs. One must distinguish between a very narrow detailed study (e.g., one study describing a prenatal care project in a given state for a limited period of time), of which there are many examples, and a comprehensive review and analysis of all projects in all states, of which there are few if any examples. The uncoupled, fragmented, and disjointed nature of the overall health service system is faithfully reflected in the kinds and numbers of research studies about elements within the system. One exception to this general characteristic is the Weckworth study mentioned earlier. Unfortunately, the results of that MCHS generated effort were not available for inclusion in this report.

Another exception is a comprehensive study that looks at one service for one type of disorder (e.g., prevention services for rubella), and we have found an excellent example in the case of the Bio-dynamics report on the Rubella Immunization

⁴⁷ *Policy Manual for Crippled Children's Division of the University of Oregon Medical School*, Oregon State Systems of Higher Education, State of Oregon.

⁴⁸ A. L. Faust and S. Stecher (eds.), "Crippled Children's Services," *Tennessee Public Health*, Vol. 20, No. 3, July-September 1971, entire issue.

⁴⁹ W. E. Deacon, *Development and Application of a Health Problem Index*, Indiana State Department of Welfare, Division of Services for Crippled Children, April 1972.

Program.⁵⁰ In taking a comprehensive look at all rubella programs, Bio-dynamics ran into many of the same system and organizational phenomena that we have by looking at a variety of programs for handicapped children. Among the many recommendations made in that report, underlying themes stressed problems of coordination, lack of program evaluation, poor to nonexistent information about programs, and personal and institutional problems with doctors, bureaucrats, and the served population.

Data Availability

The germ of an excellent accountability system exists in the very detailed, 50-state reports used to produce the general summary document, *Children Who Received Physicians' Services under the Crippled Children's Program*.⁵¹ But there are problems associated with these data. When we began this study in March 1972 we made several visits to see responsible officials in Maternal and Child Health Services and inquired directly about comprehensive data collected at the state or local level about the CCS programs. We were not informed of these documents from each state until some months later; while interviewing officials in Wyoming, they showed us the working sheets they were using to prepare the upcoming year's totals. Armed with the Federal form number, we returned to MCHS and requested all 50 state reports. We learned that MCHS had only the summary data we had been given in March, and turns over the detailed data reports on a contract to computer specialists at George Washington University who in turn produce the general summary document.

We can safely say that the Federal Government is conducting very little data-based programmatic evaluation of the CCS program. Once the computer tapes of detailed state reports have been transferred to the subcontractor at George Washington University and the summary document prepared, as far as we can determine, only slight additional analysis is made of the information.

Maternal and Child Health Service: State Plan Analysis. As part of the contract to George Washington University for its Operational and Demographic Analysis for Maternal and Child Health Project, we obtained a computer listing of all state plans for 1969. This information is summarized in the accompanying tables to indicate the kind and quality of data that are available. The basic information carried in this file deals with the kinds of programs run in the states with MCHS and CCS funds; which states are providing what kinds of services; and, by rearranging the information, total verbal pictures of all services provided for each state. The information is reasonably detailed, but limited at the same time. Except for gross total dollar values budgeted for all services for each state, there is no indication of how the dollars have been broken down by service, nor is there any indication of how many individuals received the services, the kinds of handicapping conditions served, the ages, and so forth. This is basically a listing of some 273 separate services and activities according to the states providing each. It is four years old, but it is the most up-to-date analysis available.

⁵⁰ Bio-dynamics, Inc., *Evaluation of the Rubella Immunization Program*, for HEW/ASPE, Contract No. HEW-OS-70-153, June 30, 1971.

⁵¹ MCHS Statistical Series No. 3, 1970. This report replaces NCSS Report CC-1 and reflects the switch to computer based operations.

The information in Table 8.27 shows the wide variety of services the states provide under both the MCHS and CCS programs. It reinforces our earlier view and finding on the difficulty of making whole program assessments where the contributing elements are numerous and inconsistent across all units of observation—in this case, the states. On the issue of consistency, we searched through the data in Table 8.27 for all services or activities that are provided by 45 or more state programs, taking both CCS and MCHS sponsorship together. There are only two such activities: training of health personnel—own; and services for errors of metabolism—PKU screening. When we looked for services provided in 40 or more state programs, we found two more: well-child care and cleft lip and palate programs. Dropping to 35 state programs providing the same service, we found five more activities: training of health personnel—other; casefinding programs—CCS; diagnostic CC services—comprehensive; speech therapy; and nutrition services.

The information in Table 8.27 has been condensed and summarized according to the type of service provided a handicapped child or his family directly—the basic functional categories adopted for this study. These data are represented in Table 8.28 according to source (either MCHS or CCS service) and activities. From this translation of the 273 activity and service labels used in the summary of state MCHS and CCS plans, it is quite evident that MCHS programs stress identification through screening and registration mechanisms, and prevention via immunization and other disease-specific programs. CCS is primarily concentrated on medical treatment and direction, where diagnosis is the main means of providing the latter service.

Table 8.27

MCHS AND CCS PROGRAM SERVICES AND ACTIVITIES, 1969 SURVEY

Program Services and Activities	Number of State Programs		
	MCHS	CCS	Total
Definition of standards for facilities, maternity and/or nursery	16		16
Definition of standards for facilities, day care	8		8
Definition of standards for facilities, day care for infants			0
Definition of standards for facilities, day care for migrant infants	4		4
Definition of standards for facilities, day care for children			0
Definition of standards for facilities, foster home care	3	1	4
Definition of standards for facilities, crippled children's care		13	13
Definition of standards for appliances and appliance vendors		2	2
Definition of standards for infant and child health	3		3
Definition of standards for school health programs	10		10
Definition of standards for medical specialists	2	3	5
Definition of standards for dental specialists			0
Licensing or supervision of facilities, maternity and/or nursery	8		8
Licensing or supervision of facilities, day care	7		7
Licensing or supervision of midwives	10		10
Licensing or supervision of environmental health or facilities	7		7
Licensing or supervision of facilities, foster home care	3		3
Training of health personnel for emergency childbirth	2		2
Training and instructions for midwives	6		6
Training of health personnel, own	33	15	48
Training of health personnel, other	32	5	37
Studies of maternal mortality	28		28
Studies of maternal morbidity	3		3

Table 8.27--Continued

Program Services and Activities	Number of State Programs		
	MCHS	CCS	Total
Studies of perinatal mortality	17		17
Studies of birth and fetal death information	7	1	8
Studies of neonatal mortality	2		2
Studies of infant mortality			0
Studies of illegitimacy	4		4
Studies of hyaline membrane disease	1	1	2
Studies of child abuse	2		2
Studies of handicaps			0
Studies of accidents	3		3
Studies of child hospital care	1		1
Studies of school health services	3		3
Studies of fluoridation treatment	4		4
Studies of hearing	1	1	2
Studies of birth defects	2		2
Studies of PKU	1		1
Studies of rubella	1		1
Public education and information for maternal and child health care	22		22
Public education and information for maternal and child health services	9		9
Public education and information for crippled children's conditions and care		13	13
Public education and information for school health	7		7
Public education and information for school nutrition	5		5
Public education and information for crippled children's programs		14	14
Public education and information for occupational health recommendations	2		2
Specific services for maternity care, comprehensive	33		33
Specific services for prenatal care, comprehensive	8		8
Specific services for prenatal care, clinic	28		28
Specific services for prenatal care, special consultation	5		5
Specific services for prenatal care: unwed mothers	7		7
Specific services for prenatal care: lab studies, comprehensive	7		7
Specific services for prenatal care: lab studies, rubella test	6		6
Specific services for prenatal care: lab studies, rubella immunization	1		1
Specific services for prenatal care: lab studies, rubella register	3		3
Specific services for prenatal care: lab studies, cervical cancer test	3		3
Specific services for prenatal care: lab studies, high risk mothers	3		3
Specific services for prenatal care: lab studies, blood tests	2		2
Specific services for prenatal care, teenage girls	3		3
Specific services for prenatal care, nursing care	6		6
Specific services for prenatal care, high risk mothers	7		7
Specific services for delivery care	4		4
Specific services for delivery anesthesia and analgesia	1		1
Specific services for delivery, emergency home service	2		2
Specific services for maternity, emergency medical care	2		2
Specific services for maternity, emergency transportation	2		2
Specific services for postnatal care	20		20
Specific services for infant formula	2		2
Specific services for high risk babies	10	1	11
Specific services for premature babies	27	1	28
Specific services for migrants, nursing	6		6
Specific services for genetics, counseling	11	5	16
Specific services for genetics	5	1	6
Specific services for expectant parent classes	22		22
Specific services for gonococcal conjunctivitis investigation	1		1
Specific services for maternity care mail notification program	5		5
Specific services for homemaker program	1		1
Specific services for home nursing	8		8
Obstetric nursing services	1		1
Sex and family life programs	3		3
Sex education programs	7		7
Family life education programs	9		9
Premarital blood test	2		2
Interconceptional care			0
Family health care referral services	1		1
Family health services migrant	3		3

Table 8.27--Continued

Program Services and Activities	Number of State Programs		
	MCHS	CCS	Total
Well child care	43		43
Infant and child care mail notification program	6		6
Childrens immunization clinic	32		32
Provision of immunization supplies	23	1	24
School health programs	31		31
Pediatric services comprehensive	11	2	13
Pediatric hospital services	3		3
Pediatric hospital services for crippled children		9	9
Pediatric clinic services	9	3	12
Pediatric clinic services for crippled children		8	8
Pediatric consultation services	7	5	12
Pediatric medical services for day care children	3	1	4
Pediatric screening of day care children	1		1
Pediatric medical services for foster home children	1	2	3
Pediatric screening of foster home children	1	2	3
Pediatric services for children with birth defects	2	4	6
Pediatric screening of children with birth defects	3	1	4
Pediatric follow-up of children with birth defects		2	2
Pediatric home care for children with birth defects		1	1
Pediatric surgery for children with birth defects		3	3
Register of children with birth defects	3	1	4
Services for errors of metabolism, comprehensive	2	3	5
Services for errors of metabolism, PKU screening	44	5	49
Services for errors of metabolism, PKU register	10	1	11
Services for errors of metabolism, PKU care	16	6	22
Heritable metabolic disease screening (other than PKU)	9	2	11
Heritable metabolic disease treatment (other than PKU)	3	3	6
Pediatric screening headstart	7		7
Pediatric screening migrant	4		4
Pediatric treatment migrant	5	2	7
Pediatric services for children with communicative disorders	2	3	5
Poison control	8		8
Poison control information program	13		13
Poison control treatment center	6	1	7
Poison treatment		1	1
Adolescent health program	6		6
Accident prevention	7	2	9
Accident prevention information	9		9
Accident treatment		1	1
Comprehensive care for children	11	2	13
Comprehensive care for poverty children	8	1	9
Program for prevention of child abuse	2		2
Pediatric nursing service	1	1	2
Casefinding programs, -CC	3	34	37
Program for prevention of crippling disease		1	1
Diagnostic CC services, comprehensive	1	36	37
Diagnostic CC services, emergency		3	3
Diagnostic CC services, X-rays		13	13
Diagnostic CC services, lab tests		11	11
Diagnostic CC services, planning health care program			0
Vocational CC rehabilitation		10	10
Special educational needs for CC		2	2
Comprehensive CC treatment		20	20
CC treatment clinics	1	18	19
CC treatment inpatient hospital		29	29
CC treatment outpatient hospital		19	19
CC treatment convalescent		17	17
CC treatment home care		17	17
CC treatment physical therapy	1	29	30
CC treatment occupational therapy		17	17
CC rehabilitation care		9	9
CC social services	1	16	17
Social and emotional evaluation of CC family		4	4

Table 8.27--Continued

Program Services and Activities	Number of State Programs		
	MCHS	CCS	Total
Housing for parents of hospitalized CC patients		5	5
Transportation to special CC centers	1	17	18
Homemaker services for families with CC patients	1	2	3
Provision of appliances and equipment	3	31	34
Register of children with crippling conditions	2	15	17
Education services for CC children	1	5	6
Summer camps for CC children	1	5	6
Provision of drugs for treatment	2	12	14
Orthopedic comprehensive service	1	18	19
Orthopedic diagnosis	1	25	26
Orthopedic treatment		26	26
Cystic fibrosis comprehensive service	1	12	13
Cystic fibrosis diagnosis	2	16	18
Cystic fibrosis treatment	2	19	21
Cerebral palsy comprehensive service		11	11
Cerebral palsy diagnosis	2	9	11
Cerebral palsy treatment		18	18
Convulsive disorders services	2	16	18
Cardiac conditions comprehensive service	2	15	17
Cardiac conditions examinations	2	22	24
Cardiac conditions surgery		24	24
Cardiac conditions care		27	27
Heart disease control		2	2
Rheumatic fever program	6	10	16
Rheumatic fever register	3	1	4
Plastic surgery		31	31
Endocrine disorders		2	2
Metabolic disorders		5	5
Urological disorders		8	8
Visual problems		4	4
Visual problems screening			0
Visual problems surgery		8	8
Meningomyelocoele and hydrocephalus program		3	3
Meningomyelocoele and hydrocephalus standards for care			0
Meningomyelocoele and hydrocephalus care		4	4
Diabetes program	2		2
Diabetes diagnosis	1		1
Diabetes treatment		2	2
Nephrosis program		1	1
Nephrosis tests		1	1
Nephrosis drugs		1	1
Nephrosis care		1	1
Severe burns		10	10
Developmental problems program	5	1	6
Developmental problems screening	6	2	8
Developmental problems care	5	2	7
Venereal disease programs	3		3
Oral cancer program	1		1
Mental health program	5	2	7
TB program	7		7
TB diagnosis	4		4
TB treatment	2		2
TB screening	8		8
Gastro-intestinal program		2	2
Neoplasm program	2	2	4
Chronic disease lab testing			0
Severe multiple handicapped children's program		6	6
Hemophilia program	1	3	4
Vision testing program	11	1	12
Vision testing, preschool	20		20
Vision testing, school	19		19
Vision testing, glaucoma	1	1	2
Eye care services	2	10	12

Table 8.27--Continued

Program Services and Activities	Number of State Programs		
	MCHS	CCS	Total
Eye care services, school	1		1
Schools for the blind		3	3
Vision conservation program	6	1	7
Hearing testing program	12	3	15
Hearing testing, infants	10	1	11
Hearing testing, preschool	19	3	22
Hearing testing, school	20	3	23
Hearing testing, migrants	2		2
Intelligence testing for children with hearing defects	1		1
Hearing conservation	14	15	29
Provision of hearing aids	7	19	26
Hearing therapy	5	20	25
Hearing diagnosis	11	10	21
Schools for the deaf	2	4	6
Surgery for children with hearing defects	1	7	8
Speech defect screening	7	4	11
Speech therapy	9	26	35
Speech defect diagnosis	5	5	10
Intelligence testing for children with speech defects	1		1
Speech defect surgery		3	3
Dental care and screening	18	5	23
Dental care, school children	14		14
Dental care, handicapped children	4	15	19
Dental care, migrant workers' children	5		5
Dental care, pregnant women	1		1
Dental care, preschool children	1		1
Dental care, headstart	1		1
Dental health education	8		8
Dental health education, school	8		8
Dental health education, general	4		4
Program to encourage youth to enter dental profession	2		2
Support for community dental programs	3		3
Fluoride programs	6		6
Fluoride programs, topical	8		8
Fluoride programs, community	5		5
Fluoride programs, self application	5		5
Orthodontic program	2	23	25
Cleft lip or palate program	1	41	42
Nutrition services	30	5	35
Nutrition services, day care center	8		8
Nutrition services, school lunch	13		13
Nutrition services, school weight control	4		4
Nutrition services, other institutions	9		9
Nutrition services, head start	3		3
Nutrition services, comprehensive needs	1		1
Nutrition services, mental retardation children	4		4
Nutrition services, chronic disease children	4		4
Nutrition food services	1		1
Nutrition evaluation	3		3
Mental retardation program	4	3	7
Mental retardation screening	9	1	10
Mental retardation guidance	6	3	9
Mental retardation diagnosis	14	8	22
Mental retardation treatment	9	6	15
Mental retardation services	18	5	23
Mental retardation speech services	3	2	5
Mental retardation physical therapy services		2	2
Mental retardation hearing services	2	2	4
Neurological services	3	15	18
Neuromuscular conditions, services	1	1	2
Neurosensory conditions, services	1		1

SOURCE: George Washington University, "Operational and Demographic Analysis for Maternal and Child Health Project," Computer Runs, December 1972.

Table 8.28

CLUSTERS OF MCHS AND CCS SERVICES/ACTIVITIES CONVERTED
TO HANDICAPPED FUNCTIONAL SERVICE TYPES

Type of Handicapped Service	Number of State Services Provided		
	MCHS	CCS	Total
Prevention	190	19	209
Identification	245	55	300
Direction	63	281	344
Counseling	6	9	15
Medical care	102	409	511
Education	3	12	15
Special training	21	26	47
Vocational training	0	19	19
Job placement	0	0	0
Sensory aids/equipment	10	50	60
Personal care	4	9	13
Recreation	1	5	6
Income maintenance	0	0	0
Research	53	3	56

SOURCE: Derived from Table 8.27.

9. RESEARCH: THE NATIONAL INSTITUTES OF HEALTH

OVERVIEW AND SUMMARY

The nature of the research performed by the National Institutes of Health (NIH), makes it extremely difficult to impute exact impacts of specific programs on the health and welfare of handicapped children. We indicate child-specific research that is oriented toward reducing the incidence of handicaps in general, which, of course, must also reduce handicaps among the young. The reader is warned, however, that items included and excluded as child-specific research are judgmental. These items may or may not correspond exactly to lists drawn up by specific individuals in any one of the member institutes, by officials in the Department of Health, Education and Welfare, or by other interested and responsible participants or observers.

This section describes the NIH programs that are most directly relevant to handicapped youth. Estimating dollars that accrue directly to handicapped children and flow through these member institutes is an extraordinarily difficult task. With the single exception of the National Institute of Child Health and Human Development (NICHD), the research is usually not child-specific. Instead, the work is disease-specific, and hence difficult to associate with any specific population subgroup. Nevertheless, we have conservatively estimated that some \$60-65 million of NIH research could be *directly* associated with handicapped children. The bulk of this amount comes from NICHD and the National Institute of General Medical Services (NIGMS). The following subsections, which are devoted to program descriptions, discuss this total estimate. The NIH expenditures on research for and about handicapped children are considerable, compared with the special education and vocational rehabilitation research expenditures of \$17 million and \$7 million, respectively.

The NIH present a clear example of our Catalytic model. While concentrating primarily on the innovative and stimulative features of research, NIH also provide some direct investments in facilities (e.g., genetic research and trauma centers). These functions are rationalized by (1) information brokerage arguments, (2) the importance of acquiring research economies of scale (both of talent and supporting capital investments), (3) the linking of research with professional channels of communication in order to evaluate and disseminate new knowledge, and (4) arguments that emphasize making known the general beneficial nature of the NIH work to citizens in every state.

In terms of the policy-process categories that we described earlier in this report, it is interesting to note that a variety of structural forms have evolved for each of the member institutes even though the professional peer-review aspects of selection and evaluation are more or less common to all institutes. However, the recent external interest focused on the Institutes responsible for cancer and heart diseases may be indicative of changes in what has been basically a research-oriented and researcher-run operation.

One of our findings for this report concerns the estimation phase of the policy process. During our interviews at NIH, it was not apparent that population requirements, as evidenced in demographically based estimates of the nature and changes in the composition of the handicapped population, are being effectively reflected in the setting of research priorities. For example, there is little evidence that the demonstrable changes in the character of the handicapped youth population to include more congenital, multiple, and chronic conditions are being mirrored in significant shifts in research budgets associated with these conditions. When population characteristics are captured in the estimation process, it is primarily by concerned researchers and apparently not by officials responsible for the research itself. At some level of administrative responsibility, such calculations should be routinely made.

The NICHD and NIGMS contribute the largest share of research directly aimed at reducing the diseases and disorders of handicapped children. In NICHD, the program most closely concerned with handicapped children is in the area of mental retardation, while NIGMS has concentrated a large portion of its effort on genetic diseases and trauma research. Other basic research efforts include

- Sensory-neural studies under the auspices of the National Institute for Neurological Diseases and Stroke (NINDS).
- Studies of congenital and developmental abnormalities and more specific diseases of the eye by the National Eye Institute (NEI).
- Cleft lip and palate work by the National Institute of Dental Research (NIDR).
- Heart and lung studies, including the development of improved surgical and prosthetic equipment, by the National Heart and Lung Institute (NHLI).
- Studies of allergic, immunological, and infectious diseases, including venereal disease and other bacteriological and viral infections, by the National Institute of Allergy and Infectious Disease (NIAID).
- Research on chronic renal failure and inherited diseases of metabolism, by the National Institute of Arthritis, Metabolic, and Digestive Diseases (NIAMDD).

With very few exceptions, it is impossible to trace and impute directly the research dollars spent on any specific segment of the handicapped youth population. NIH programs do have impacts; but given the unpredictable nature of research, it is very hard to calculate many direct and immediate payoffs from the work. Is the work relevant or useful? Certainly. It is just that it is very difficult to keep a clean accounting of the impacts.

In summary, our main observations are the following:

- A very small fraction of the NIH health research is handicapped-child specific.
- Of research on handicapped youth for all services, the NIH medical contribution is by far the largest.

NATIONAL INSTITUTE OF CHILD HEALTH AND HUMAN DEVELOPMENT (NICHD)

The NICHD, like the other NIH institutes, makes grants available to research organizations, hospitals, health departments, institutions of higher education, and other nonprofit organizations primarily for basic research and research training. The five major programs of the Institute are (1) perinatal biology and infant mortality, (2) growth and development, (3) mental retardation, (4) population and reproduction, and (5) adult development and aging. The first three deal directly with child health. In addition to grants, the Institute also supports research through the contract mechanism.

In FY 1972, nearly \$50 million was awarded in grants and contracts in the Child Health programs of NICHD, as shown in Table 9.1, and an additional \$6 million was spent on intramural research, conferences, scientific information dissemination, and other direct operations. By comparison, the estimated available funds for the Child Health programs in FY 1973 will decrease to \$53 million, and the Administration budget request for FY 1974 drops still further to \$51 million. Meanwhile, the number of grant applications received annually has been increasing more rapidly than available funds, with the result that NICHD has been able to support a diminishing proportion of those who apply each year.¹

As mentioned above, three of the programs of NICHD are directly concerned with child health, but the greatest emphasis on handicapped youth is found in the Mental Retardation program. The primary mission of this program is to develop and support research aimed at preventing mental retardation, and when this is not possible, to effect its amelioration. In FY 1972, the NICHD investment in mental retardation grants and contracts totaled \$19 million. A major aspect of the program has been the development and implementation of 12 Mental Retardation Research Centers, authorized by Congress in 1963. All of these Centers are now operational, and core support for their administration, facilities, and program planning was \$5.86 million in FY 1972. In addition to the core grants, many research and training grants in these Centers support more than 600 investigators, representing a broad range of basic, clinical, and applied sciences. They provide a resource for multidisciplinary and collaborative research between biomedical and behavioral scientists to better understand the complex causes, pathogenesis and modes of prevention, treatment, and amelioration of mental retardation.

Although the main emphasis in the Growth and Development and Perinatal Biology and Infant Mortality programs is on the normal development of infants and children, much of the research supported by both of these programs provides basic knowledge which is ultimately essential for the treatment or prevention of various handicapping conditions. In addition, both of these programs support some research that is directly concerned with health problems which could result in permanent handicaps.

The Growth and Development program supports research in the mechanisms of biological growth, developmental immunology, developmental pharmacology, nutrition, physical growth, developmental behavioral biology, learning and cognitive development, human communication and personality, and social growth. Currently,

¹ Letter from L. Freedman, Chief, Program Statistics and Analysis Branch, NICHD, to G. Brewer, The Rand Corporation, June 7, 1973.

Table 9.1

NATIONAL INSTITUTE OF CHILD HEALTH AND HUMAN DEVELOPMENT:
GRANTS AND CONTRACTS IN CHILD HEALTH, FY 1972

Mechanism of Support	Total	Perinatal Biology and Infant Mortality	Growth and Development	Mental Retardation
A. Funds (in thousands)				
Research grants	\$36,988	\$10,321	\$12,039	\$14,628
Training grants	6,269	2,316	2,524	1,428
Fellowships	573	279	248	45
RCP awards ^a	1,931	632	895	404
Total grants	45,760	13,547	15,706	16,506
Contracts	4,020	510	1,191	2,318
Total grants and contracts	49,780	14,058	16,898	18,824
B. Number of Projects				
Research grants	551	224	228	99
Training grants	84	31	36	17
Fellowships	58	27	27	4
RCP awards ^a	80	26	37	17
Total grants	773	308	328	137
Contracts	34	10	8	16
Total grants and contracts	807	318	336	153

SOURCE: NICHD, Program Statistics and Analysis Branch, June 7, 1973.

^aResearch Career Program.

the program is developing an area of expanded emphasis in adolescence, as it has been shown that there is relatively little hard information on the many crucial biological and behavioral changes taking place during the adolescent years.

As an example of research in growth and development which is directly concerned with handicaps in childhood, several longitudinal projects are under way in which the goal is to assess the severity and permanence of the effects of malnutrition on physical and mental development. Another example is research related to learning disorders and dyslexia. These are known to be abnormalities of pattern perception, and as a means of elucidating the processes involved, research is being conducted to increase knowledge of the developmental maturation of brain function. NICHD expenditures for grants and contracts for research and research training in child growth and development amounted to \$17 million in FY 1972.

The objective of the Perinatal Biology and Infant Mortality program is to promote a coordinated program of research and training that will enhance understanding of pregnancy and maternal health, embryonic development, fetal growth, and infant well-being through the first year of life. Efforts are directed toward reducing the country's infant mortality rate, ameliorating infant morbidity, and narrowing

the gap between the identification of new knowledge and its incorporation into the delivery of health care. Some of this research impacts directly on preventing handicaps. Examples include research on the consequences of maternal complications during pregnancy, such as toxemia and diabetes, as well as on factors adversely affecting the development of the fetus in utero, such as malnutrition. Also relevant is research on adaptation of the neonate to postnatal life, including the problems engendered by such disorders as respiratory distress, hyperbilirubinemia, hypoglycemia, and erythroblastosis fetalis. In FY 1972, support for all programs in perinatal biology and infant mortality amounted to \$14 million.

A major point to be made about NICHD programs is that their overall impact on handicapped children is general and not easily assessed, as is often the case for research projects. It is known, for example, that better prenatal care and nutrition will reduce prematurity and that reduced prematurity reduces the odds that children will be born handicapped. However, it is a difficult proposition to assess the direct results of any one of the research projects that NICHD undertakes.²

NATIONAL INSTITUTE FOR NEUROLOGICAL DISEASES AND STROKE (NINDS) ³

A major program area of research grant support is in the communicative disorders (hearing, language, and speech), amounting to approximately \$10 million in FY 1973. A directed research program is also under way, at the early planning and preliminary funding stage, on communication disorders. Interesting features of the program include (1) the development of a means to test for hearing loss in early infancy, (2) studies of diseases connected with childhood hearing loss, (3) research to improve hearing aids generally, (4) research tracing the implications of high fever with hearing loss, and (5) investigations into the possibilities of developing other sensory channels when the "ordinary" ones have become inoperative.

The perinatal research project in 14 collaborating institutions is studying neurological and sensory disorders in approximately 60,000 children. This project was funded at \$7.5 million in FY 1973, and is directly concerned with caring for handicapped children who have cerebral palsy; congenital defects; brain damage; minimal brain dysfunction; mental retardation; and hearing, language, and speech defects.

Epilepsy has been a long-time interest of NINDS, and continuing work is in progress to determine better surgical and chemical means for treating and correcting this defect. In addition, a directed program of contract-support research is under way in developing and field testing new anticonvulsant drugs. The epilepsy program was funded at approximately \$4 million in FY 1973.

In its broad charter to study diseases of the nervous and sensory systems, NINDS is concentrating on the development of certain prostheses for the blind. Roughly categorized, this research is concerned with (1) the neurological pathways that produce sensations of sight, (2) determining how these pathways might be

² Interview, L. Freedman, Chief, Program Statistics and Analysis Branch, and S. Hollies, Program Analysis Section, NICHD, March 15, 1972.

³ Interview, Dr. O. Malcolm Ray, Extra-Mural Programs, NINDS, March 15, 1972.

replicated or stimulated when they are not functioning naturally, and (3) surgical and chemical means for correcting deficiencies of these systems.

NATIONAL EYE INSTITUTE (NEI)

Under Title IV, Part F of the Public Health Service Act, the NEI had an estimated total research budget of \$24.95 million in FY 1973. By category of disease, \$6.2 million was devoted to the retina and choroid, \$3.7 million to sensory motor disorders, \$3.0 million to corneal diseases, \$2.7 million to glaucoma, and approximately \$530,000 to congenital and developmental abnormalities. The remaining bulk of the budget was spread rather widely among a number of other disease classes.⁴

The primary program emphasis of NEI is on basic research in anatomy and biochemistry of the eye. Being phased out are Model Reporting Area programs, which are state voluntary associations for the registry of the blind, on the grounds that they "are just not valid and they certainly are not very reliable."⁵ It is extremely hard to assess the child-specific portion of NEI's effort. At the least, \$530,000 is being spent on congenital defects; determining the proportion of the more basic and general work that impacts on children depends on the assumptions one makes about the proportion of children in the total population who will not be afflicted as a result of research-based improvements in eye health.

NATIONAL INSTITUTE OF DENTAL RESEARCH (NIDR)

As indicated in our discussion of the Crippled Children's Service, cleft lip or palate are relatively frequent handicaps in the general population. NIDR estimates that between 6000 and 7000 children are born annually with cleft lip/palate and that corrective surgery and rehabilitative services for those individuals totals some \$100 million per annum. NIDR support for research into cleft lip/palate and other related malformations and disorders amounted to approximately \$2 million in FY 1970.⁶

NATIONAL HEART AND LUNG INSTITUTE (NHLI)

The Medical Applications Program of NHLI is concentrating some \$10.0 million on devices to detect, prevent, and treat medically handicapping conditions of the heart and lung. For example, research and development is being financed for (1) a

⁴ U.S. Department of Health, Education and Welfare, *Justifications of Appropriation Estimates for Committee on Appropriations—FY 1973*, Vol. IV, p. 146 (hereafter cited as *Justifications of Appropriation Estimates*).

⁵ Interview, Staff of the Program Planning Division, NEI, March 16, 1972.

⁶ Memo from Mr. Bruce Carson to the Assistant Secretary for Health and Scientific Affairs, March 3, 1972.

heart-assist pump, (2) improving oxygenation equipment to aid in open heart surgery, and (3) artificial prosthetic devices to replace diseased and/or damaged portions of the heart. While the research is not child-specific, the equipment under development will be used in the care and treatment of many children having heart and lung disorders.

NATIONAL INSTITUTE OF ALLERGY AND INFECTIOUS DISEASES (NIAID)

NIAID supports work that is directed toward discovering methods for controlling allergic, immunological, and infectious disease problems. Major programs and centers for allergic diseases are in operation, but the number of children who are served and who benefit from these efforts is not readily estimable. General research into bacterial and staphylococcal infections is also under way with NIAID support, which is estimated to total \$1.795 million for FY 1973. Drug resistance mechanisms, venereal diseases, and viral infectious diseases are each specifically considered in the NIAID budget, and each doubtless has some impact on the reduction of handicaps to children; the exact impact, however, is impossible to determine. It is interesting to note that with venereal disease reaching epidemic proportions among the nation's youth (as well as adults), the total budget for research for this class of diseases is \$500,000 in FY 1973.⁷

NATIONAL INSTITUTE OF ARTHRITIS, METABOLIC AND DIGESTIVE DISEASES (NIAMDD)

The NIAMDD makes grants for a variety of research enterprises, several of which have some direct bearing on handicapped children and youth. For instance, NIAMDD supports work in orthopedics (mostly related to arthritic conditions), diabetes, and "other inherited diseases of metabolism," in which cystic fibrosis is the one most directly related to children, although a variety of diseases and syndromes are presently being studied with an eye to the development of preventive techniques. Endocrinology, including digestive diseases and studies of nutrition are also carried out under NIAMDD auspices.

Under the Kidney and Urologic Diseases segment of the NIAMDD budget, some \$10.162 million was earmarked for studies in FY 1973. Chronic renal diseases are classed with several other degenerative urological diseases, and all are being attacked with a total estimated research budget of \$10.162 million in FY 1973. One child suffering from chronic renal failure requires, by a conservative estimate, about \$25,000 per year to sustain life. This means that only 150 to 200 children can be supported for the same amount of money that the NIAMDD budget devoted to research on this problem. Or, put another way, it is surprising how little money is

⁷ U.S. Department of Health, Education and Welfare, *Justifications of Appropriation Estimates*, pp. 13-22.

being spent on investigating the causes and cures of the disorder as compared with the staggering amounts that are being spent on its treatment.

NATIONAL INSTITUTE OF GENERAL MEDICAL SCIENCES (NIGMS)

The programs of NIGMS are extremely varied. However, the research on prevention and treatment of trauma, genetically caused handicaps, and improvements in anesthesiology are the three classes of work that apply directly to the population of handicapped children.

Beginning in 1971, the establishment of 12 genetic research and training centers, at an average cost of \$600,000, was authorized in medical centers throughout the country. (Einstein College of Medicine in New York is one such center.) These centers are working in four broad program areas including (1) the identification of carriers of genetic disease, (2) mapping of human chromosomes, (3) genetic control of the human cell, and (4) establishing a bank of human cell culture lines to enhance the practice of genetic medicine. It is estimated by NIGMS that "one out of every 250 newborn babies have major chromosome defects that lead inevitably to mental retardation, sterility, or serious physical abnormalities."⁸ Work for genetics and genetics centers was funded at a rate of \$33.5 million in FY 1973.

The trauma program focuses on ways to minimize or prevent the crippling effects often found in victims of automobile accidents or those who are severely burned. It is estimated that trauma (primarily as a result of accidents) claims the lives of more children between the ages of 1 and 14 than the next six leading causes of death combined. Some fraction of the estimated total of \$8.3 million in the FY 1973 Clinical Sciences budget went for trauma research and centers.

Another specific program within NIGMS's budget for General Clinical Sciences is directed toward improving procedures for helping premature infants suffering from acute respiratory distress. The exact amount of this cannot be determined from the budget, but is something less than the total \$2.17 million that was allocated for Anesthesiology and Diagnostic Radiology Centers taken together.⁹ In total, the portion of the NIGMS's annual budget primarily relevant to handicapped youth is at least \$33,500,000.

⁸ Ibid., p. 61.

⁹ Ibid., pp. 61,68.

10. MENTAL HEALTH AND MENTAL RETARDATION PROGRAMS FOR HANDICAPPED YOUTH

OVERVIEW AND SUMMARY

The proliferation of different Federal programs supporting services to mentally ill or retarded youth has mostly been discussed in earlier sections, along with other programs that are aimed at the general population, or at all types of handicapped persons, rather than specifically at the mentally handicapped. In this section, we present an overview of programs aimed primarily at the mentally handicapped; discuss the Federal role in those programs; present available descriptive data, including estimates of program expenditures and number of persons served; and, finally, discuss problems cited by state mental health and mental retardation agency administrators. Unlike previous sections of this report, research and data availability are not discussed in a separate subsection but are integrated throughout.

Programs primarily providing services to the mentally handicapped are estimated to have assisted over 700,000 youth aged 0-21 in 1970. Total expenditures in this area for youth were at least \$898.2 million in 1970, of which the Federal share was \$74.7 million, or 8.4 percent. The breakdown of these figures, shown in Tables 10.1 and 10.2, indicates that the expenditures were predominantly for residential inpatient care of the mentally retarded (54 percent) and the mentally ill (30 percent). However, the greatest number of youth were served in outpatient facilities for the emotionally disturbed and mentally ill. Of Federal programs, the two largest were the Developmental Disabilities program, primarily serving retarded persons, and the NIMH Community Mental Health Center (CMHC) program. A breakdown of the estimated expenditures by type of handicap is shown in Table 10.3; the retarded or otherwise developmentally disabled received the largest share with 61 percent.

There is no clearly defined Federal role nor are there even well-understood goals underlying the provision of services to the mentally retarded and mentally ill populations of children and youth.

With respect to the mentally retarded, even the basic diagnosis of "mental retardation" is a fundamental operational problem. For example, in the Mental Retardation Clinics operated under the auspices of the Maternal and Child Health Service, nearly half of those referred and then medically diagnosed were not mentally retarded at all. In the case of the Rehabilitation Services Administration's Developmental Disabilities program, we found the definition issue, not having been resolved in the basic legislation, was referred by the Secretary to a study group for

Table 10.1

ESTIMATED MENTAL HEALTH AND RETARDATION PROGRAM EXPENDITURES FOR
HANDICAPPED YOUTH, 1970

Program	Expenditures	
	Federal	Total
Residential care of the mentally retarded	---	\$479,529,000
Inpatient care of the mentally ill	---	267,000,000
Outpatient care of the mentally ill (except Community Mental Health Centers)	---	64,000,000
NIMH (including CMHC)	49,000,000	54,000,000
Developmental disabilities (FY 1972)	25,000,000	33,000,000
President's and Secretary's Committees on Mental Retardation (FY 1971)	660,000	660,000
Total	\$74,660,000	\$898,189,000

SOURCE: For data sources and estimation methods, see "Programs for Mentally Retarded, Emotionally Disturbed, and Mentally Ill Children," in this section.

Table 10.2

ESTIMATED NUMBER OF HANDICAPPED YOUTH RECEIVING MENTAL HEALTH
AND RETARDATION SERVICES, 1970

Program	Number of Handicapped Youth
Residential mental retardation care	103,073
Inpatient care of the mentally ill (FY 1969) ..	149,000
Outpatient care of the mentally ill (FY 1969) .	570,000
Developmental disabilities (FY 1971)	88,000

SOURCE: For data sources and estimation methods, see "Programs for Mentally Retarded, Emotionally Disturbed, and Mentally Ill Children," in this section.

Table 10.3

ESTIMATED EXPENDITURES FOR MENTAL HEALTH AND RETARDATION PROGRAMS
FOR YOUTH BY TYPE OF HANDICAP, 1970

Handicap	Estimated Expenditures
Mentally retarded, developmentally disabled	\$549,189,000
Emotionally disturbed, mentally ill	349,000,000
Total	\$898,189,000

SOURCE: For data sources and estimation methods, see "Programs for Mentally Retarded, Emotionally Disturbed, and Mentally Ill Children," in this section.

deliberation. On this score, we do not fault those responsible for the various programs, but merely note that the issue is a terribly difficult one having grave implications for program planning, funding, and evaluation.

It is hard to plan when information is in short supply, or nonexistent, but this is the case for practically every program we observed touching the lives of mentally handicapped children and youth.

The question of cost is also thorny, but here at least there are some data, much of which indicate that the general skyrocketing of medical expenses has also impacted on mentally retarded children, irrespective of whether they are inpatients or outpatients, although the impact on the former is far greater than on the latter. The cost factor is one of the major elements (humanitarian concern for better care and alternatives to a mental institution being others) that accounts for the trend away from institutionalization and toward outpatient care for the mentally retarded.

Mentally retarded people in hospitals account for the greatest expenditures, even though only about 1 in 25 of the mentally retarded youth receives residential inpatient services. Since 1950, the institutionalized and mentally retarded portion of the total population for all ages has grown only slightly. The proportion of youthful residents has grown, however, especially those under age five, whose inpatient rate per 100,000 of their cohort's population nearly quadrupled between 1950 and 1970. The average costs per patient-day for maintaining persons in institutions basically tripled between 1960 and 1970, reaching a figure of \$12.70. These costs vary considerably across the states; five states spent less than \$7 per patient-day in 1970, while six states spent over \$15.

Of the mentally ill youth served, 21 percent are inpatients, while 66 percent are served in psychiatric outpatient clinics, 11 percent are served in Community Mental Health Centers, and 2 percent are served in day treatment centers. The trend to lessen the ratio of inpatients to outpatients noted for all ages of the mentally ill combined is not mirrored in the child and youth subset of the population, where it has remained relatively stable or even increased slightly. Costs have not remained constant, particularly for the institutionalized mentally ill, who in 1970 numbered some 150,000 in the 0-21 age range and whose inpatient maintenance costs totaled at least \$267 million.

In our overall investigation of Federal programs for the mentally retarded and ill, we were struck with the extent to which effort is dispersed throughout the government; nonetheless, there are several Federal programs that concentrate on these populations, and we examined them in some detail.

The National Institute of Mental Health has six distinct program areas which have some direct impact on these populations. (1) The Community Mental Health Centers program is the largest; (2) child-specific mental health research is the next largest; followed (in descending order of total expenditures, not necessarily by the fraction that is child-specific) by (3) mental health training grants; (4) St. Elizabeths Hospital; (5) mental health fellowships; and (6) hospital improvement grants.

A second focus is the Developmental Disabilities Services and Facilities Construction Act which is the responsibility of the Rehabilitation Services Administration and was in FY 1972 funded at \$49.54 million, some portion of which benefited children and youth.

The following summarizes our observations about mental health and mental retardation programs for handicapped youth:

- The Federal share of the total expended on programs primarily intended for the mentally handicapped is not large.
- Population and cost data are not well known, even by those having direct operational responsibility for programs. High quality evaluation is practically nonexistent, but given the poor status of primary data on the populations, that is to be expected. In short, no one really knows who is doing what to whom and with what effect.
- Coordination among the baffling array of programs for the mentally retarded and ill is more bureaucratic rhetoric than actuality.
- Research is neither large-scale nor is it generally child-specific. As compared with estimated expenditures for maintenance of the population of more than \$800,000,000 per year, and the lack of knowledge, the total of all research seems quite low.
- Is service provision inadequate? Many say so. The problem of funding is pervasive, as it has been for nearly all of the services and programs that we report on. One result of increased budgetary pressures at the state and local levels has been the closure of state institutions for the mentally handicapped. Rather than an alternative to institutionalization, the community based programs have become increasingly a replacement where the question remains whether such shifts result in less costly or rather less visible expenses.
- Is service provision inequitable? Probably, but data to assess the nature and extent of inequity are not readily available.

ROLES AND GOALS

In no other area is there more confusion about the appropriate Federal role as there appears to be with respect to the mentally retarded and ill. Literally all of our characteristic role models exist in some Federal mental health or mental retardation program, but each exists only partially and none is developed sufficiently well that it dominates. The amorphous character of the system is partly explained just in terms of the sheer number of functionally disparate agencies that have programs affecting mentally retarded and ill children.

The Direct Operations model is, for instance, partially evident at St. Elizabeths Hospital. For the mentally ill and some few retarded in their CMHC in Washington, D.C., this is a prime source of direct service, and it is located administratively within the National Institute of Mental Health. But then there exist partial examples of the Controllership model too. There is the Community Mental Health Center program, whose funds are basically provided from Federal (NIMH) sources, whose guidelines and policies are set down in Federal offices, whose research component is even separately mandated with Federal funds, but whose services are delivered by the states and localities. A form of the Special Revenue Sharing model exists to a certain extent in the Developmental Disabilities program, whose annual budget of \$50 million or so primarily benefits state planning and coordinating bureaucracies, but the evaluative Plus of this type of model is practically absent. Another form of Special Revenue Sharing, but with some degree of the evaluation Plus, also exists in the Maternal and Child Health Service's Mental Retardation Clinics. The Catalyt-

ic model is embodied to some degree in the research and training efforts of NIMH, in some of the research efforts of the Rehabilitation Services Administration, and in some of the activities sponsored by the Bureau of Education for the Handicapped in the Office of Education. However, there appears to be little real coordination among these assorted research efforts.

In fact, if any one model of the existing system exists at all, it is one that we did not characterize: the "Disorganization" model.

Health Services and Mental Health Administration (HSMHA) has, one might imagine, some direct substantive reason to be preeminent among competing bureaucracies, but we find that the Social Rehabilitation Service, the Social Security Administration, and even the Office of Education all have more resources to bring to bear on the mentally retarded segment of the overall population than does HSMHA. While each has more dollars, each also has far less direct and substantive commitment to provide services to the mentally retarded and ill populations; such is simply *not* the main order of business for any of them.

Functions, lacking any clearly stated objectives or well-delineated authority, are likewise numerous and underdeveloped. There is some research and development going on, but, even using liberal estimates of its extent, the total effort is clearly less than the unanswered questions, the size, or even the maintenance costs of the afflicted population would suggest to be adequate. Seed money projects are being run in many programs, but none alone, or even in the aggregate, appears to be solving the problems. Demonstrations, attended with much rhetoric and political fanfare, abound; but, given the poor state of basic information, no one really knows how well these efforts have fared or whether they are worth more widespread adoption.

There have been large investments in services, hospitals, manpower and research; but any investment strategy that may exist has not worked well in the sense that there is no way of determining the dividends paid by these investments, or whether another mix of investments might not have done the job as well or better.

Rationales are at least as numerous as the dozens of programs and agencies dispensing services to the mentally retarded and mentally ill; but no one of them emerges as the clearly dominant justification for these services.

The policy process responsible for the legislation, programs, and the overall system serving the mentally retarded and ill is also underdeveloped. Because research and development efforts are small on a scale relative to needs, not coordinated to any large degree, and detached from the many and varied agencies meting out services to the population, the initial or invention phase of the process is embryonic. Estimation is largely nonexistent because insufficient data are available to begin making much more than crude estimates about the needs of the population. Selection remains an isolated, basically political process, generally unsupported by factual information about the relative needs and demands of the population. Implementation has a few isolated bright spots; but, in the overall perspective, who really knows what is working well, and why? Evaluation is a piecemeal proposition not closely related to the prior phases of the policy process, e.g., invention, estimation, and selection. And where evidence of termination exists, as in the case of state mental hospital closures, choices appear to have been made as much for budgetary reasons as for the impacts the closures will have on the specific, afflicted populations.

PROGRAMS FOR MENTALLY RETARDED, EMOTIONALLY DISTURBED, AND MENTALLY ILL CHILDREN

Previous sections have described agencies providing services to children with any type of physical or mental handicap. Special education, public welfare, and vocational rehabilitation agencies serve all handicapped persons; Maternal and Child Health and Crippled Children's Service programs also have disease categories and coverage for both physically and mentally handicapped. This section discusses agencies primarily serving persons commonly labeled mentally retarded or mentally ill.

Mental Retardation

Mental retardation is a pervasive and quite common problem in all societies. Defining the terms that describe the disorder is at best a problematic undertaking and at worst an impossible one.¹ Reacting to a variety of descriptors of mental retardation (e.g., age at onset, IQ, mental age, educability), an attempt by the American Association on Mental Deficiency to combine the concepts of functional proficiency and measured intelligence seems a reasonable enough place to begin:

Mental retardation refers to subaverage general intellectual functioning which originates in the developmental period and is associated with impairment in adaptive behavior.²

Notwithstanding definitional (and other) problems, the 1970 White House Conference on Children, using estimates made by an earlier Presidential Committee,³ stated that in 1970 there were about 2.5 million mentally retarded children in the United States under the age of 20. Of these, some 75 percent were mildly retarded (educable), 15 percent were moderately retarded (trainable), 8 percent were severely retarded (many trainable), and 2 percent were profoundly retarded (unable to care for themselves).⁴ This estimate squares reasonably well with work done by Ronald W. Conley in his pioneering effort on measuring the economics of mental retardation programs. Conley considers a wide variety of data in estimates of mental retardation, disaggregated by age,⁵ which are 679,000 children aged 0-4, and 1,916,000 aged

¹ The definition problem is thorny to say the least. We are not about to resolve it here, but recommend that the interested reader consult the following representative works: R. Heber, "Mental Retardation: Concept and Classification," in E. R. Trapp and Paul Himelstein (eds.), *Readings on the Exceptional Child*, Appleton-Century-Crofts, New York, 1962, pp. 69-81; American Association on Mental Deficiency, *A Manual on Terminology and Classification in Mental Retardation*, Monograph Supplement to the American Journal of Mental Deficiency, 1961; and E. A. Doll, "The Essentials of an Inclusive Concept of Mental Deficiency," *American Journal of Mental Deficiency*, Vol. 46, 1941, pp. 214-219.

² AAMD, *A Manual on Terminology*.

³ The President's Committee on Employment of the Handicapped, *Report*, Washington, D.C., n.d. (reference to Chart 87). Another important source book is Joint Commission on Mental Health of Children, *Crisis in Child Mental Health: Challenge for the 1970s*, Harper and Row, New York, 1969.

⁴ White House Conference on Children 1970, *Profiles of Children*, Government Printing Office, Washington, D.C., 1971, p. 51.

⁵ A preliminary report is contained in R. W. Conley, "An Assessment of the Economic and Non-Economic Costs and Benefits of Mental Retardation Programs," in J. S. Cohen et al., *Benefit-Cost Analysis for Mental Retardation Programs: Theoretical Considerations and a Model for Application*, Institute for the Study of Mental Retardation and Related Disabilities, Ann Arbor, Michigan, 1971. The definition of mental retardation used was basically an IQ of less than 70. Conley's complete work will be published in mid-1973.

5-19, for a total of 2,595,000 aged 0-19. It is important to note that these estimates are for the *total* young retarded population, not those identified and receiving services, a considerably smaller figure, as we shall see momentarily.

The 1970 White House Conference also estimated that of the 100,000 to 200,000 babies born each year who are mentally retarded, one-fourth of their disorders are linked to genetic abnormalities, infections of the mother during early pregnancy, birth accidents, postnatal infections, or trauma. "In the remaining cases, inadequacies in prenatal and perinatal health care, nutrition, child rearing and social and environmental opportunities are suspected as causes of retardation."⁶ That is not a great deal of information with which to formulate policy, but it is representative of the current state of knowledge about the root causes of mental retardation, an area clearly needing much more systematic attention.⁷

Budget Allocations for Mentally Retarded Persons of All Ages

In 1970, the Secretary's Committee on Mental Retardation calculated total obligations for mental retardation activities for all age groups throughout the Department of Health, Education, and Welfare.⁸ Summary data presented in Table 10.4 break down the \$557.7 million spent by HEW in FY 1970, and attest concisely to the grossly fragmented authority and responsibility that presently exist in providing services for the mentally retarded. A similar picture could be shown for each of the other types of handicaps. The Social and Rehabilitation Service (SRS) leads the five major segments of HEW in expenditures for FY 1970, with a total estimated for all SRS accounts of \$287.9 million. Of this total, grants to states for medical assistance (\$100.0 million), income maintenance (\$79.2 million), and basic state vocational rehabilitation grants (\$54.5 million) were the largest components of assistance to the mentally retarded. Income maintenance represented all of the Social Security Administration's \$145.1 million share. The Office of Education added \$71.4 million, the bulk of which came from funds under Title I of the Elementary and Secondary Education Act. Health Services and Mental Health Administration ranked fourth overall with a total expenditure of \$31.2 million. And the National Institutes of Health added some \$21.5 million, nearly half of which was for research on child health.

It is important to note that the expenditures are for persons of all ages. Most of the items in Table 10.4 have already been discussed specifically for children in earlier sections under general types of service agencies. Several programs have not been mentioned before, however, because they are provided through agencies primarily serving the mentally impaired, and we shall cover these after examining the composition of the mentally retarded and mentally ill populations of children.

⁶ White House Conference, *Profiles of Children*.

⁷ One's expectation that research into the causes and cures for mental retardation would be likewise diffuse is borne out by examination of the pertinent programs of institutes in the National Institutes of Health and Health Services and Mental Health Administration.

⁸ Secretary's Committee on Mental Retardation, *Mental Retardation Activities of the Department of Health, Education and Welfare*, U.S. Department of Health, Education and Welfare, January 1971.

Table 10.4

U.S. DEPARTMENT OF HEALTH, EDUCATION AND WELFARE: OBLIGATIONS FOR
MENTAL RETARDATION ACTIVITIES, FY 1970 AND 1972

(In \$ thousand)

Activity	1970	1972 Budget Estimate
Health Services and Mental Health Administration		
Services		
Comprehensive Health Planning and Services	525	0
Maternal and Child Health and Welfare	12,990	12,990
Total	13,515	12,990
Training		
Mental Health Research and Services	441	400
Comprehensive Health Planning and Services	50	0
Maternal and Child Health and Welfare	14,765	19,336
Total	15,256	19,736
Research		
Mental Health Research and Services	600	0
St. Elizabeths Hospital	0	0
National Health Statistics	0	0
Maternal and Child Health and Welfare	1,842	1,600
Total	2,442	1,600
Construction		
Hill-Burton	0	0
Other		
Mental Health Research and Services (abstracts)	0	0
Grand total	31,213	34,326
National Institutes of Health		
Training		
Neurology and Stroke Activities	6,171	4,676
Child Health	1,471	1,431
Total	7,642	6,107
Research		
Neurology and Stroke Activities	4,795	4,974
Child Health	9,089	11,879
Total	13,884	16,853
Grand total	21,526	22,960
Office of Education		
Services		
Title I, ESEA, Educationally deprived children	33,000	35,600
Title III, ESEA, Supplementary centers	3,650	4,900
Education for the Handicapped Act, Part B	9,200	10,160
Education for the Handicapped Act, Part C, Section 623	590	950
Vocational Education Act, Part B	11,500	11,500
Total	57,940	63,110
Training		
Education for the Handicapped Act, Part D	10,391	10,500
Education Professions Development Act	1,400	1,400
Total	11,791	11,900
Research		
Cooperative Research Act	76	---
Education for the Handicapped Act, Part E	1,602	1,600
Total	1,678	1,600
Other		
Library Services and Construction Act	15	30
Grand total	71,424	76,640
Social Security Administration		
Income Maintenance		
Estimated Benefit Payments from Trust Funds	143,000	176,800
Trust Fund Obligations Incurred to Adjudicate		
Claims of Beneficiaries	2,100	2,500
Grand total	145,100	179,300

Table 10.4--continued

Activity	1970	1972 Budget Estimate
Social and Rehabilitation Service		
Services		
Rehabilitation Services and Facilities		
Basic State Grants	54,500	74,100
Innovation	223	0
Expansion Grants	108	144
Facility Improvement Grants	3,600	3,400
Formula Grants for the Developmentally Disabled	0	5,608
Services for the Developmentally Disabled	20,172	18,975
Total	78,603	102,227
Grants to States for Public Assistance		
Child Welfare Services	--	(a)
Medical Assistance	100,000	100,000
Special Programs for the Aging		
Foster Grandparents Program	5,800	5,000
Title III Community Grant Programs	100	50
Total	5,900	5,050
Total (services)	184,503	207,277
Training		
Rehabilitation Services and Facilities		
Vocational Rehabilitation	1,282	290
Services for the Developmentally Disabled	3,359	4,600
Health Services Activities	113	0
Total	4,754	4,890
Research and Training		
Research and Training Centers ^b	902	950
Total (training)	5,656	5,840
Research		
Research and Training		
Research and Demonstrations ^c	1,216	695
Social and Rehabilitation Activities Overseas (special foreign currency program)	300	400
Total (research)	1,516	1,095
Construction		
Rehabilitation Services and Facilities		
Formula Grants for the Developmentally Disabled	0	5,607
Construction of University Affiliated Facilities	0	0
Construction of Community Service Facilities	16,870	0
Rehabilitation Facilities and Construction Grants	123	0
Total	16,993	5,607
Total (construction)	16,993	5,607
Income Maintenance		
Grants to States	79,200	116,700
Grand total	287,868	336,519
Office of the Secretary		
Secretary's Committee on Mental Retardation	(111)	110
President's Committee on Mental Retardation	580	650
Total	580	760
GRAND TOTAL, ALL FUNDS	557,711	650,505

SOURCE: Secretary's Committee on Mental Retardation, *Mental Retardation Activities of the Department of Health, Education and Welfare*, Department of Health, Education and Welfare, Washington, D.C., January 1971, pp. 71-75.

^aData not available.

^bIncludes Child Welfare Training Programs.

^cIncludes Child Welfare Research and Demonstration and Special Programs for the Aging, Title IV, Research and Demonstration.

Institutions Serving the Mentally Retarded

The 1970 Annual Census of Patients in Public Institutions for Mentally Retarded, prepared by SRS, indicates that while the rate of new admissions per 100,000 population is relatively stable or slightly decreasing for all age cohorts (Table 10.5), both the percentage representation and the rate per 100,000 for all those under age 19 is increasing; furthermore, it is more pronounced for those aged 5 or less (Table 10.6). As of the 1970 census, one in every twenty-five, or 99,053, of the total estimated number of mentally retarded persons aged 21 or less in the United States was

Table 10.5

NUMBER, PERCENT DISTRIBUTION, AND RATE PER 100,000 POPULATION OF FIRST ADMISSIONS TO PUBLIC INSTITUTIONS FOR THE MENTALLY RETARDED: UNITED STATES, 1950-1970

Year	Total	Age at Admission						
		<5	5-9	10-14	15-19	20-24	25-34	35 and Over
Number								
1950	10,960	1,743	2,337	2,557	2,022	729	780	792
1955	12,092	2,266	3,086	2,825	1,913	611	668	723
1960	13,534	2,264	3,734	3,532	2,312	507	455	730
1965	15,008	2,031	4,486	4,155	2,659 ^b	639	440	598
1970 ^a	12,063	1,668	3,405	3,114	2,378 ^b	422 ^c	468	588
Percent								
1950	100.0	15.9	21.3	23.3	18.5	6.7	7.1	7.2
1955	100.0	18.7	25.5	23.4	15.8	5.1	5.5	6.0
1960	100.0	16.7	27.6	26.1	17.1	3.7	3.4	5.4
1965	100.0	13.5	29.9	27.7	17.7	4.3	2.9	4.0
1970 ^a	100.0	13.8	28.2	25.8	19.7	3.7	3.9	4.9
Rate Per 100,000								
1950	7.3	10.7	17.6	22.9	19.4	6.6	3.3	1.2
1955	7.5	12.4	18.0	21.2	18.0	6.5	2.8	1.0
1960	7.6	11.1	19.9	20.8	17.8	5.0	2.0	1.0
1965	7.8	9.9	21.9	21.9	15.9 ^d	5.1 ^d	2.0	0.7
1970 ^a	6.0	9.5	16.7	15.1	8.4 ^d	8.4 ^d	1.9	0.7

SOURCE: U.S. Department of Health, Education and Welfare, *Public Institutions for the Mentally Retarded--Trends in Caseload, Manpower, Expenditures, Social and Rehabilitation Service*, July 1968 (updated to 1970).

^aData for 1970 in this table and Table 10.6 are based on 1970 Annual Census of Patients in Public Institutions for Mentally Retarded. 1970 data shown in other tables in this chapter are based on another survey. Therefore, there are minor discrepancies in the numbers.

^bFor 1970 age 15-20.

^cFor 1970 age 21-24.

^dFor 1970 age 15-24.

Table 10.6

NUMBER, PERCENT DISTRIBUTION, AND RATE PER 100,000 POPULATION OF RESIDENTS IN PUBLIC INSTITUTIONS FOR THE MENTALLY RETARDED: UNITED STATES, 1950-1970

Year	Total	Age at End of Year						
		<5	5-9	10-14	15-19	20-24	25-34	35 and Over
Number								
1950	128,145	1,949	7,146	13,922	18,912	16,785	27,962	41,469
1955	143,548	3,617	11,643	17,429	19,769	15,739	27,897	47,454
1960	163,730	3,474	14,512	23,744	25,727	18,101	27,459	50,713
1965	187,305	3,933	17,457	28,797	32,419	22,370	28,741	53,588
1970 ^a	187,177	7,198	21,474	29,247	36,373 ^b	19,062 ^c	27,727	46,096
Percent								
1950	100.0	1.5	5.6	10.9	14.7	13.1	21.8	32.4
1955	100.0	2.5	8.1	12.1	13.8	11.0	19.4	33.1
1960	100.0	2.1	8.9	14.5	15.7	11.0	16.8	31.0
1965	100.0	2.1	9.3	15.4	17.3	11.9	15.4	28.6
1970 ^a	100.0	3.9	11.5	15.6	19.4	10.2	14.8	24.6
Rate Per 100,000								
1950	85.3	11.9	53.7	124.9	181.6	151.6	118.8	64.1
1955	88.4	19.8	67.9	130.6	185.7	167.3	118.4	67.2
1960	91.9	17.1	77.2	139.8	197.9	177.1	123.6	66.2
1965	97.6	19.2	85.1	151.9	194.1 ^d	178.8 ^d	132.8	66.0
1970 ^a	92.8	41.9	108.0	140.6	161.1 ^d	161.1 ^d	112.7	54.4

SOURCE: U.S. Department of Health, Education and Welfare, *Public Institutions for the Mentally Retarded--Trends in Caseload, Manpower, Expenditures, Social and Rehabilitation Service*, July 1968 (updated to 1970).

^aData for 1970 in this table and Table 10.5 are based on 1970 Annual Census of Patients in Public Institutions for Mentally Retarded. 1970 data shown in other tables in this chapter are based on another survey. Therefore, there are minor discrepancies in the numbers.

^bFor 1970 age 15-20.

^cFor 1970 age 21-24.

^dFor 1970 age 15-24.

resident in a public institution.⁹ At a daily expenditure rate of \$12.70 per resident patient,¹⁰ the estimated annual expenditure rate is \$459,233,000 for mentally retarded youth.

State mental hospitals sometimes serve the mentally retarded as well as the mentally ill, and there too the trend seems reasonably well established that in the past 20 years the percentage distribution of adults is slowly but steadily decreasing

⁹ Estimate based on linear interpolation of data shown in Table 10.6.

¹⁰ U.S. Department of Health, Education and Welfare, *Residents in Public Institutions for the Mentally Retarded, Current Facility Reports, July 1, 1969--June 30, 1970*, Social and Rehabilitation Service, 1971. Some small but undetermined percentage of these funds are from Federal sources. In addition, some small but again undetermined percentage may also be reported in education budgets.

while that of children is increasing (see Table 10.7). An estimated total of 4015 mentally retarded persons aged 21 or less were served in state mental hospitals in 1970.¹¹ Using the average total annual measurable cost of \$5055¹² per person served in 1970 leads to an estimated annual expenditure rate of at least \$20,296,000 for mentally retarded youth in state mental hospitals.

Table 10.7

NUMBER AND PERCENT DISTRIBUTION OF RESIDENT PATIENTS DIAGNOSED AS MENTALLY DEFICIENT IN STATE MENTAL HOSPITALS BY AGE: UNITED STATES, 1950-1970

Year	Total	<15	15-24	25-34	35-44	45-54	55-64	65+
Number								
1950	48,226	582	4,636	9,337	10,520	10,362	7,639	5,150
1955	47,620	481	3,526	8,584	10,599	10,601	7,997	5,833
1960	43,486	424	3,271	6,782	9,627	9,892	7,907	5,583
1965	35,727	748	4,101	5,526	8,210	8,942	7,360	4,840
1970	30,327	1,147	4,097	4,168	5,038	6,249	5,405	4,223
Percent								
1950	100.0	1.2	9.6	19.4	21.8	21.5	15.8	10.7
1955	100.0	1.0	7.4	18.0	22.3	22.3	16.8	12.2
1960	100.0	1.0	7.5	15.6	22.1	22.7	18.2	12.8
1965	100.0	1.9	10.3	13.9	20.7	22.5	18.5	12.2
1970	100.0	3.8	13.5	13.8	16.6	20.6	17.8	13.9

SOURCE: Unpublished data from National Institute of Mental Health, HSMHA, reproduced in Secretary's Committee on Mental Retardation, *Mental Retardation Activities of the Department of Health, Education and Welfare*, U.S. Department of Health, Education and Welfare, Washington, D.C., January 1971, p. 38.

Data for private institutions are quite sketchy, and the only informational reporting requirement that routinely generates data merely notes the number of facilities in each state and crudely identifies the types of programs available. As indicated in Table 10.8, in 1969 there were 708 private facilities offering services for the mentally retarded throughout the United States; California (250), Ohio (43), and Pennsylvania (43) together accounted for nearly half of the total. Four states reported no private institutions at all: Alaska, Arkansas, Idaho, and Wyoming.

State Cost Factors for the Institutionalized Mentally Retarded. On a national average, daily maintenance expenditures for the mentally retarded in public institutions have nearly tripled since 1960.¹³ While the growth rates have

¹¹ Estimate based on linear interpolation of data shown in Table 10.7.

¹² Conley, p. 79.

¹³ Kenneth McCaffree, "The Cost of Mental Health Care Under Changing Treatment Methods," in H. Schulberg et al. (eds.), *Program Evaluation in the Health Fields*, Behavioral Publications, New York, 1969, pp. 452-457, provides a brief, well-rounded discussion of costing problems.

Table 10.8

PROGRAMS OFFERED IN PRIVATE FACILITIES FOR THE MENTALLY RETARDED BY STATE AND TYPE OF PROGRAM, 1969

State	Total Facilities	Facilities Offering All Six Programs ^a	Facilities Offering Programs for:						Facilities Offering Other Programs	Facilities with No Programs Offered
			Educable Children	Trainable Children	Profoundly Retarded Children	Adults	Vocational Rehabilitation	Medical Rehabilitation		
United States	708	11	178	222	139	125	97	55	128	238
Alabama	1	---	---	---	---	---	---	---	---	1
Alaska	---	---	---	---	---	---	---	---	---	---
Arizona	7	---	3	5	4	1	1	1	---	---
Arkansas	---	---	---	---	---	---	---	---	---	---
California	250	8	66	78	55	43	25	23	57	77
Colorado	4	---	1	1	1	---	---	---	---	3
Connecticut	7	---	1	---	3	---	---	---	---	3
Delaware	4	---	2	4	3	---	---	---	---	---
D.C.	2	---	2	1	1	1	---	---	1	---
Florida	14	---	6	7	2	2	2	1	2	5
Georgia	1	---	---	1	---	---	---	---	---	---
Hawaii	21	---	---	---	---	1	3	2	2	12
Idaho	---	---	---	---	---	---	---	---	---	---
Illinois	44	---	5	5	6	14	5	2	2	22
Indiana	6	---	---	---	---	---	---	1	2	3
Iowa	16	---	2	2	2	5	1	1	3	7
Kansas	6	---	---	---	---	1	---	1	1	4
Kentucky	1	---	1	1	---	1	1	---	1	---
Louisiana	5	---	3	4	1	1	2	---	---	---
Maine	16	---	1	1	1	2	1	1	2	12
Maryland	6	1	3	5	3	1	3	1	1	---
Massachusetts	6	---	5	4	1	1	2	1	1	---
Michigan	14	---	4	5	---	1	1	---	2	6
Minnesota	24	---	7	8	4	4	2	1	3	9
Mississippi	1	---	---	---	---	---	---	---	---	1
Missouri	18	---	3	6	2	3	3	1	4	6
Montana	1	---	---	---	---	---	---	---	---	1
Nebraska	3	---	---	1	---	---	---	1	---	1
Nevada	3	---	---	---	---	1	---	---	1	1
New Hampshire	3	---	1	2	---	---	---	1	---	1
New Jersey	16	---	5	7	4	1	5	1	3	4
New Mexico	2	---	---	1	---	---	---	---	1	1
New York	29	1	14	12	5	5	7	2	5	8
North Carolina	6	---	1	1	3	2	---	---	---	1
North Dakota	1	---	---	---	---	---	---	---	1	---
Ohio	43	---	3	7	10	8	4	3	10	15
Oklahoma	10	---	3	3	5	2	2	---	1	3
Oregon	7	---	2	3	---	2	1	---	---	3
Pennsylvania	43	---	19	24	10	5	10	3	9	8
Rhode Island	2	---	---	1	1	---	---	---	---	1
South Carolina	1	1	1	1	1	1	1	1	---	---
South Dakota	1	---	---	---	---	---	---	---	---	1
Tennessee	7	---	1	3	1	---	1	1	1	2
Texas	25	---	4	7	5	4	2	1	3	10
Utah	11	---	---	1	1	5	1	1	3	2
Vermont	2	---	---	---	---	1	---	---	---	1
Virginia	6	---	3	5	---	2	4	1	3	---
Washington	5	---	1	---	---	1	1	1	2	2
West Virginia	1	---	---	---	---	---	---	---	---	1
Wisconsin	6	---	5	5	4	1	6	1	1	---
Wyoming	---	---	---	---	---	---	---	---	---	---

SOURCE: Unpublished data from the National Center for Health Statistics' 1969 survey of the Master Facility Inventory.

^aExcludes other programs.

climbed steadily upward in all states, not all state growth rates have conformed to the average (Table 10.9). First consider the five states with the highest average daily rates in 1970: California (\$16.38), Georgia (\$15.92), Colorado (\$15.73), Pennsylvania (\$15.38), and Kansas (\$15.26). (Alaska is a special case and also the most expensive at \$35.62; we disregard it for the purposes of calculating trends and rates of change.) The 1960 group average for these five states was \$5.01 per day per patient; this figure was \$15.73 in 1970, an increase of 214 percent. On the other hand, consider the five states having the lowest daily rates in 1970: Mississippi (\$4.61), South Dakota (\$6.28), Alabama (\$6.37), Idaho (\$6.53), and North Dakota (\$6.62). The 1960 group average for these states was \$2.61 per day per patient; this figure was \$6.08 in 1970, an increase of 133 percent. Costing services to mentally retarded children is difficult; figuring out what *not* providing these services will in time cost society is next to impossible.

MCHS Mental Retardation Clinics. The Maternal and Child Health and Crippled Children's Service programs of the Health Services and Mental Health Administration currently support in whole or part some 154 mental retardation clinics in which some 60,800 children received diagnostic and counseling services during FY 1971. Male patients outnumbered females at a consistent rate of 3 to 2 in all age categories, the 5- to 9-year-old cohort was the most frequently served (45.1 percent of the total), and the median age of those receiving services was 7.2 years (Table 10.10).¹⁴

When one looks at Mental Retardation Clinics supported partially or fully by MCHS in FY 1971, according to the states providing the services, Pennsylvania with three clinics is serving the most children, some 4913. New York with three clinics serves 4555, and Indiana with three serves 4309.

Washington State operates the most clinics (14), North Carolina is second (11), and California and Virginia are tied at third (10) (Table 10.11).

New patients are referred to the clinics most frequently by private physicians (31.7 percent of the total); schools are second (18.4 percent); hospitals are third (16.5 percent); and public health services are fourth (9.0 percent). In states where this pattern did not hold, the dominant variation reversed schools and private physicians as the most prevalent referral source (Table 10.12).

New patients are classed in Table 10.13 according to the primary diagnosis of causative condition. Of the 27,988 new referred patients, only 49.1 percent were classified as mentally retarded. What this demonstrates quite clearly is the profound difficulty that exists in determining what mental retardation means in operational terms and then matching the appropriate and needed services accordingly. The problem of definition and classification of those served is exacerbated in the case of those who were medically classified.¹⁵ As noted in Table 10.14, 32.2 percent of the new patients were diagnosed as "Uncertain cause—functional reaction alone manifest"; and an additional 16.9 percent were diagnosed as "Unknown cause—structur-

¹⁴ Expenditures and youth receiving these services have already been counted under the appropriate MCHS and CCS headings in Sec. 8.

¹⁵ The classification of mentally retarded or mentally ill is not to be taken casually. See T. Szasz, *Law, Liberty, and Psychiatry*, Macmillan, New York, 1963; O. G. Simmons, *The Mental Patient Comes Home*, John Wiley, New York, 1963; and a host of others who have been deeply concerned with the labeling problem and its various, mostly unpleasant, side effects. An excellent empirical case detailing the problems of public opinion and mental health is presented in H. J. Halpert, *Public Opinions and Attitudes Toward Mental Health*, Public Health Service Publication No. 1045, Washington, D.C., 1963.

Table 10.9

DAILY MAINTENANCE EXPENDITURES PER PATIENT UNDER TREATMENT^a IN PUBLIC INSTITUTIONS
FOR THE MENTALLY RETARDED, 1960 AND 1970

State	1960	1970
United States	4.20	11.64
Alabama	2.53 ^b	6.37
Alaska	---	35.62
Arizona	2.73	7.32
Arkansas	3.99	8.86
California	6.33	16.38
Colorado	4.47	15.73
Connecticut	5.20	12.69
Delaware	4.71	11.78
D.C.	7.08 ^b	11.82
Florida	5.03	10.75
Georgia	3.61	15.92
Hawaii	---	11.84
Idaho	3.69	6.53
Illinois	3.03	13.53
Indiana	3.86	12.09
Iowa	3.46	14.35
Kansas	6.37	15.26
Kentucky	---	9.74
Louisiana	3.53	10.86
Maine	4.21	13.97
Maryland	4.67	11.38
Massachusetts	4.33	11.96
Michigan	5.60	12.67
Minnesota	4.09 ^c	12.01
Mississippi	1.63	4.61
Missouri	3.23	9.75
Montana	2.90	8.08
Nebraska	2.34	7.39
Nevada	---	---
New Hampshire	4.49	7.75
New Jersey	4.09 ^b	10.75
New Mexico	4.84	12.35
New York	4.27 ^c	12.08
North Carolina	4.09 ^b	10.91
North Dakota	3.03	6.62
Ohio	3.97	8.12
Oklahoma	1.86 ^b	11.42
Oregon	3.33	11.53
Pennsylvania	4.25	15.38
Rhode Island	4.67	15.01
South Carolina	2.35	6.80
South Dakota	2.16	6.28
Tennessee	2.47	10.92
Texas	3.00	8.67
Utah	2.85	10.48
Vermont	3.61	9.79
Virginia	3.43	7.20
Washington	5.55	14.89
West Virginia	3.93	11.49
Wisconsin	5.73	14.11
Wyoming	4.14	8.00

SOURCE: U.S. Department of Health, Education and Welfare, *Public Institutions for the Mentally Retarded--Trends in Caseload, Manpower, Expenditures, Social and Rehabilitation Service*, July 1968 (updated to 1970).

^aPatients under treatment is defined as the resident patients at the beginning of the year plus total admissions.

^bEstimated.

^cData underestimated as one institution reported only by number of patients under care and not corresponding maintenance expenditures.

Table 10.10

NUMBER AND PERCENT OF PATIENTS SERVED IN MENTAL RETARDATION CLINICS
BY THEIR STATUS AND AGE

Age Group	All Patients		New Patients		Other Patients	
	Total	Percent	Total	Percent	Total	Percent
All ages	60,859	100.0	27,988	100.0	32,871	100.0
Under 6 months	772	1.3	598	2.1	174	0.5
6-11 months	1,193	2.0	832	3.0	361	1.1
1-2 years	5,903	9.7	3,400	12.1	2,503	7.6
3-4 years	10,353	17.0	5,325	19.0	5,028	15.3
5-9 years	27,422	45.1	12,058	43.1	15,364	46.7
10-14 years	12,031	19.9	4,705	16.8	7,376	22.4
15-17 years	2,146	3.5	743	2.7	1,403	4.3
18-20 years	989	1.6	327	1.2	662	2.0
Median age	7.2	---	6.6	---	7.7	---

SOURCE: U.S. Department of Health, Education and Welfare, *Mental Retardation Clinic Services, 1971, Maternal and Child Health Service, 1972.*

al reactions manifest." In other words, 49.1 percent of the 79.6 percent who were medically classified had unknown causes. It appears that research is needed into possible ways of improving basic data collection on the reasons for patient's mental retardation and in time into the basic causes of retardation itself.

When the generic categories of causation are further broken down into the specific medical classifications (Table 10.14), we find that the largest group ("Uncertain cause—functional reaction alone manifest") breaks down principally into the vague and unilluminating categories of "Other," 13.13 percent, and "Cultural-familial," 8.78 percent. For the second most prevalent generic classification, "Prenatal influence," congenital causes were the most reported at a total of 9.76 percent, and Mongolism was second at 8.15 percent. The "Other" category of "Unknown cause—structural" is as nonilluminating as "Other" for "Uncertain cause—functional." In the case of "Trauma," anoxemia at birth was the most frequently reported cause at 5.76 percent.

The difficulty in diagnosing retardation is further emphasized by data presented in Table 10.15. Of the new patients referred in FY 1971, 38.9 percent were reported as having "No retardation in measured intelligence." Combining this subgroup with "Borderline" (20.5 percent) accounts for 59.4 percent, well over half of the total new referred patients whose level of intelligence was determined.

Many youth are being served under the Mental Retardation Clinic program, but who they are, what they are suffering from, and what they actually need are all at best imperfectly known. One may conjecture that referral, or the direction service and function, is not well developed.

Emotional Disturbance and Mental Illness

Population Characteristics. Overview data on services for the emotionally disturbed and mentally ill of all ages for 1955, 1968-69, and 1971 are presented in

Table 10.11

NUMBER OF PATIENTS SERVED IN MENTAL RETARDATION CLINICS
BY STATUS AND STATE, FY 1971

State	Number of Clinics	Number of Patients			New as a Percent of Total
		Total	New	Other	
United States	154	60,859	27,988	32,871	46.0
Alabama	2	1,389	587	802	42.3
Alaska	1	122	102	20	83.6
Arizona	2	884	512	372	57.9
Arkansas	1	592	444	148	75.0
California	10	1,475	783	692	53.1
Colorado	6	1,309	821	480	62.7
Connecticut	4	424	339	85	80.0
Delaware	1	336	153	183	45.5
D.C.	3	969	405	564	41.8
Florida	2	1,418	553	865	39.0
Georgia	3	687	431	256	62.7
Guam	---	---	---	---	---
Hawaii	1	278	138	140	49.6
Idaho	1	591	148	443	25.0
Illinois	3	1,173	618	555	52.7
Indiana	3	4,309	1,854	2,455	43.0
Iowa	2	783	548	235	70.0
Kansas	1	2,330	1,001	1,329	43.0
Kentucky	2	953	607	346	63.7
Louisiana	---	---	---	---	---
Maine	2	222	88	134	39.6
Maryland	1	913	653	260	71.5
Massachusetts	3	948	502	446	53.0
Michigan	4	2,927	1,078	1,849	36.8
Minnesota	2	593	282	311	47.6
Mississippi	2	558	249	309	44.6
Missouri	3	781	542	239	69.4
Montana	1	36	18	18	50.0
Nebraska	1	420	193	227	46.0
Nevada	2	786	264	522	33.6
New Hampshire	---	---	---	---	---
New Jersey	7	1,304	925	379	70.9
New Mexico	2	618	259	359	41.9
New York	3	4,555	1,059	3,496	23.2
North Carolina	11	2,679	1,407	1,272	52.5
North Dakota	1	157	104	53	66.2
Ohio	6	2,553	787	1,766	30.8
Oklahoma	2	643	404	239	62.8
Oregon	5	1,000	448	552	44.8
Pennsylvania	3	4,913	1,437	3,476	29.2
Puerto Rico	1	2,383	820	1,563	34.4
Rhode Island	1	1,082	457	625	42.2
South Carolina	1	194	132	62	68.0
South Dakota	---	---	---	---	---
Tennessee	3	1,506	683	823	45.4
Texas	6	2,440	1,518	922	62.2
Utah	3	405	262	143	64.7
Vermont	1	250	97	153	38.8
Virgin Islands	---	---	---	---	---
Virginia	10	2,487	1,088	1,399	43.7
Washington	14	1,654	948	706	57.3
West Virginia	2	555	301	254	54.2
Wisconsin	3	1,275	939	336	73.6
Wyoming	---	---	---	---	---

SOURCE: U.S. Department of Health, Education and Welfare, *Mental Retardation Clinic Services, 1971*, Maternal and Child Health Service, 1972.

Table 10.12

NUMBER OF NEW PATIENTS IN MENTAL RETARDATION CLINICS BY SOURCE OF REFERRAL AND STATE, FY 1971

State	Total	Private Physician	Public Health Agency	Crippled Children's Program	Mental Health Agency	Hospital	Welfare Agency	School	Other Community Agency	Other
United States	27,988	8815	2532	548	524	4630	1370	5148	1530	2891
Alabama	587	206	79	19	8	18	34	144	47	22
Alaska	102	25	18	0	6	5	5	13	1	19
Arizona	512	92	77	11	8	38	43	127	53	63
Arkansas	444	100	103	33	4	30	54	82	20	18
California	783	178	113	20	61	103	67	64	29	148
Colorado	821	185	44	6	14	239	43	120	72	98
Connecticut	739	123	27	7	9	44	41	35	26	27
Delaware	153	100	10	6	1	2	5	17	9	3
D.C.	405	53	54	3	3	52	4	107	13	116
Florida	553	174	33	17	1	41	36	79	23	149
Georgia	431	80	96	21	9	27	24	104	41	29
Guam	---	---	---	---	---	---	---	---	---	---
Hawaii	138	13	32	19	2	1	5	39	3	24
Idaho	148	24	30	16	3	0	4	37	28	6
Illinois	618	111	18	37	19	203	47	95	21	67
Indiana	1,854	940	76	9	15	385	39	304	36	50
Iowa	548	279	4	14	3	16	41	121	15	55
Kansas	1,001	135	3	25	4	476	8	237	34	79
Kentucky	607	148	261	20	6	22	5	88	27	30
Louisiana	---	---	---	---	---	---	---	---	---	---
Maine	88	67	14	1	0	2	2	1	1	0
Maryland	653	18	8	0	2	576	2	6	11	30
Massachusetts	502	237	10	0	35	23	7	90	23	77
Michigan	1,078	514	27	8	19	334	0	94	20	62
Minnesota	282	26	12	9	1	0	38	91	43	62
Mississippi	249	86	39	0	1	1	16	36	34	36
Missouri	542	145	6	4	0	274	16	46	37	14
Montana	18	16	1	0	0	0	0	0	0	1
Nebraska	193	75	2	3	6	43	8	20	6	30
Nevada	264	31	61	2	15	0	38	42	27	48
New Hampshire	---	---	---	---	---	---	---	---	---	---
New Jersey	925	341	24	37	9	31	90	201	57	135
New Mexico	259	42	35	1	1	1	29	89	17	44
New York	1,059	197	76	31	40	181	65	184	130	155
North Carolina	1,407	346	327	16	49	49	71	341	47	161
North Dakota	104	46	5	0	2	0	8	24	13	6
Ohio	787	381	31	4	12	134	7	60	73	85
Oklahoma	404	181	82	1	1	65	21	11	3	39
Oregon	448	85	32	0	19	10	20	192	21	69
Pennsylvania	1,437	785	16	21	23	490	20	35	26	20
Puerto Rico	820	16	80	33	24	50	24	470	9	114
Rhode Island	457	309	9	2	4	119	0	5	7	2
South Carolina	132	81	24	16	0	0	8	1	2	0
South Dakota	0	0	0	0	0	0	0	0	0	0
Tennessee	683	275	56	4	6	79	52	82	81	48
Texas	1,518	694	60	6	37	159	64	367	67	64
Utah	262	25	15	0	0	10	3	186	2	21
Vermont	97	46	5	6	2	1	5	13	7	12
Virgin Islands	---	---	---	---	---	---	---	---	---	---
Virginia	1,088	329	204	15	4	129	39	229	51	88
Washington	948	180	101	8	7	61	51	204	57	279
West Virginia	301	118	36	27	7	16	4	72	3	13
Wisconsin	939	157	56	0	22	89	152	133	157	173
Wyoming	0	0	0	0	0	0	0	0	0	0

SOURCE: U.S. Department of Health, Education and Welfare, *Mental Retardation Clinic Services, 1971*, Maternal and Child Health Service, 1972.

Table 10.13

NUMBER AND PERCENT OF NEW PATIENTS MENTALLY RETARDED,^a THOSE NOT MENTALLY RETARDED, AND THOSE NOT DETERMINED AS TO MEDICAL CLASSIFICATION

Medical Classification	Number of New Patients	Percent of All New Patients	Percent of Those Medically Classified
Number of new patients	27,988	100.0	---
Classification not determined	5,705	20.4	---
Classification determined	22,283	79.6	100.0
Not mentally retarded	8,539	30.5	38.3
Mentally retarded	13,744	49.1	61.7
Mentally retarded/primary diagnosis of condition causing or associated with mental retardation	13,744	100.0	---
Infection	851	6.2	3.8
Intoxication	440	3.2	2.0
Trauma or physical agent	1,611	11.7	7.2
Metabolism, growth, or nutrition	517	3.8	2.3
New growths	182	1.3	0.8
Prenatal influence	3,397	24.7	15.2
Unknown cause with structural reactions manifest	2,316	16.9	10.4
Uncertain cause with functional reaction alone manifest	4,430	32.2	19.9

SOURCE: U.S. Department of Health, Education and Welfare, *Mental Retardation Clinic Services, 1971, Maternal and Child Health Service, 1972.*

^aBy primary diagnosis of condition causing or associated with mental retardation.

Table 10.16. Inpatient care as a proportion of total care decreased from 77.4 percent in 1955 to 39.1 percent in 1971. Of the total care in 1955, some 48.9 percent was accounted for by state and county mental hospitals; by 1971 this had decreased to 18.1 percent. Not only has the trend to outpatient care been pronounced, but the impact of the Community Mental Health Centers, carrying some 19.1 percent of the 1971 caseload, is significant.

Cost considerations certainly must be taken into account as one component underlying the trend noted in the type of facility providing care. The total daily expense for each patient in non-Federal psychiatric hospitals in 1950 was \$2.43; in 1960 it had climbed to \$4.91; and by 1970 the figure was up to \$16.63.¹⁶

The concept of cost as associated with mental illness presents some theoretical and practical difficulties well beyond the scope and purpose of this report. However, in a thorough consideration of these problems, Rashi Fein, in 1958, judged that the total direct and indirect costs of mental illness in the United States were in the

¹⁶ U.S. Department of Commerce, *Statistical Abstract of the United States 1972*, Washington, D.C., 1972, p. 74, table: "Hospital Expense per Patient Day: 1950-1970." Comparable rates for all hospitals in each of the three periods were as follows: 1950 = \$7.98; 1960 = \$16.46; and 1970 = \$53.95.

Table 10.14

NUMBER AND PERCENT OF MENTALLY RETARDED NEW PATIENTS IN MENTAL RETARDATION CLINICS
BY MEDICAL CLASSIFICATION AND SUBGROUP, FY 1971

Primary Medical Diagnosis of Condition Causing or Associated with Mental Retardation	Patients	
	Number	Percent
Total mentally retarded	13,744	100.00
Infection	851	6.19
Prenatal infection	372	2.71
Postnatal cerebral infection	479	3.49
Intoxication	440	3.20
Toxemia of pregnancy	163	1.19
Other maternal intoxications	51	0.37
Bilirubin encephalopathy (Kernicterus)	120	0.87
Post-immunization encephalopathy	14	0.10
Other	92	0.67
Trauma or physical agent	1,611	11.72
Prenatal injury	192	1.40
Mechanical injury at birth	291	2.12
Anoxemia at birth	792	5.76
Postnatal injury	336	2.44
Metabolism, growth, or nutrition	517	3.76
Cerebral lipoidosis, infantile	18	0.13
Other disorders of lipoid metabolism	24	0.17
Phenylketonuria	142	1.03
Other disorders of protein metabolism	33	0.24
Galactosemia	16	0.12
Other disorders of carbohydrate metabolism	27	0.20
Arachnodactyly	6	0.04
Hypothyroidism	73	0.53
Gargoylism (Lipochondrodystrophy)	31	0.23
Other	147	1.07
New growths	182	1.32
Neurofibromatosis	85	0.62
Trigeminal cerebral angiomas	10	0.07
Tuberculous sclerosis	59	0.43
Intracranial neoplasm, other	28	0.20
Prenatal influence	3,397	24.72
Cerebral defect, congenital	989	7.20
Cerebral defect, congenital associated with primary cranial anomaly	352	2.56
Laurence-Moon-Biedl syndrome	9	0.07
Mongolism	1,120	8.15
Other	927	6.74
Unknown cause--structural reactions manifest	2,316	16.85
Diffuse sclerosis of brain	40	0.29
Cerebral degeneration	39	0.28
Prematurity	866	6.30
Other	1,371	9.98
Uncertain cause--functional reaction alone manifest	4,430	32.23
Cultural-familial	1,207	8.78
Psychogenic, associated with environmental deprivation	585	4.26
Psychogenic, associated with emotional disturbance	554	4.03
Psychotic (or major personality) disorder	279	2.03
Other	1,805	13.13

SOURCE: U.S. Department of Health, Education and Welfare, *Mental Retardation: Public Services, 1971*, Maternal and Child Health Service, 1972.

Table 10.15

NUMBER AND PERCENT OF NEW PATIENTS IN MENTAL RETARDATION CLINICS
BY INTELLIGENCE LEVEL, FY 1971

Intelligence Level ^a	Number	Percent
New patients, total	27,988	---
Not determined	6,709	---
Total determined	21,279	100.0 ^b
Intelligence level		
No retardation in measured intelligence	8,270	38.9
Borderline retardation -1 ^c	4,357	20.5
Mild retardation -2	3,779	17.8
Moderate retardation -3	2,605	12.2
Severe retardation -4	1,479	7.0
Profound retardation -5	789	3.7

SOURCE: U.S. Department of Health, Education and Welfare, *Mental Retardation Clinic Services, 1971*, Maternal and Child Health Service, 1972.

^aLevel of deviation in measured intelligence and retardation in measured intelligence.

^bPercents do not add to 100 due to rounding.

^c-1 is minus one.

neighborhood of \$3.0 billion per year.¹⁷ However, this estimate is not disaggregated for children and youth.

Overview data on services for mentally ill children are shown in Table 10.17 and indicate some significant differences in the type of facilities providing services to children and youth as compared with the population at large. Although the trend for all ages of patients has been toward fewer inpatients as a proportion of the total population served in the age group, this is not the case for the child subset of the population. In fact, there was a slight increase, from 15.1 percent to 20.7 percent, over the period from 1966 to 1969. Still, the majority of children are served through psychiatric outpatient facilities, and at 66.3 percent of the total this is considerably greater than for the general population's use of these services at a rate of 40.1 percent. The relative use of inpatient care has not declined for the 0-21 age group, particularly for state and county mental hospitals (the class of facilities where the most marked decline occurs for the total population).

Estimated total expenditures in 1970 for inpatient care of handicapped children is \$267 million, assuming that the per-day figure of \$16.63 in non-Federal psychiatric hospitals is valid for young patients, and assuming that the average days in mental hospitals is the same for a child as it is for the average person.¹⁸

¹⁷ Rashi Fein, *Economics of Mental Illness*, Basic Books, New York, 1958; these numbers are not "hard," as attested to in this caveat: "The large differences between the estimates contained in this study and some of the popular estimates of the costs of mental illness certainly bear witness to the fact that one should approach published data on costs with a high degree of caution." P. 125.

¹⁸ Unpublished data of the American Hospital Association of Chicago, reported in *Statistical Abstract of the United States 1972*, indicate a 1970 rate per 1000 population of 862 total days in mental hospitals. Thus, the 203,211,926 United States residents spent an estimated 175.2 million patient-days in mental hospitals in 1970.

Table 10.16

MENTAL ILLNESS, ALL AGES: PATIENT CARE BY TYPE OF FACILITY,
1955-1971

(In thousands and percentages)

Type of Facility	1955	1968	1969	1971
Outpatient				
Psychiatric outpatient	379 (22.6)	1507 (44.7)	1603 (43.9)	1668 (40.1)
Community mental health centers	NA ---	272 ^a (8.0)	373 ^a (10.3)	797 ^a (19.1)
Day treatment services	NA ---	NA ---	NA ---	75 (1.8)
Total outpatient	379	1779	1976	2540
Inpatient				
State & county mental hospitals	819 (48.9)	792 (23.4)	767 (21.0)	754 (18.1)
Private	123 (7.3)	118 (3.5)	124 (3.4)	145 (3.5)
General hospitals (with psychiatric service)	266 (15.9)	559 (16.5)	535 (14.7)	556 (13.3)
Residential treatment centers	NA	NA	NA	NA
Veterans Administration	88 (5.3)	134 (3.9)	187 (5.1)	169 (4.09)
Community mental health centers	(a)	(a)	(a)	(a)
Total inpatient	1296	1602	1613	1624
Total all facilities	1675 (100.0)	3381 (100.0)	3589 (100.0)	4164 (100.0)

SOURCE: 1955, 1968, and 1969 data from U.S. Department of Commerce, *Statistical Abstract of the United States 1972*, p. 76. (Derived from U.S. Department of Health, Education and Welfare, *Statistical Note 23*, Public Health Service, April 1970, and *Statistical Note 58*, Public Health Service, January 1972.)

1971 estimates from Mrs. Shirley Willner, co-author of *Statistical Note 23*, Biometry Division, NIMH, March 21, 1973 telephone conversation.

NOTE: Estimated. Includes resident patients at beginning of year or those on active rolls of outpatient clinics, plus those admitted during year.

^aThe total CMHC caseload, both in and outpatient, is listed under the outpatient category.

Table 10.17

MENTAL ILLNESS, AGED 0-21: PATIENT CARE EPISODES BY TYPE
OF FACILITY, 1966, 1968, 1969

(In thousands and percentages)

Type of Facility	1966 ^a	1968 ^a	1969 ^b
Outpatient			
Psychiatric outpatient	399 (84.9)	526 (77.0)	477 (66.3)
Community mental health centers	NA	52 ^c (7.0)	80 ^d (11.1)
Day treatment services	NA ---	NA ---	13 (1.8)
Total outpatient	399	578	570
Inpatient			
State & county mental hospitals	27 (5.9)	26 (4.0)	54 (7.5)
Private	8 (1.7)	7 (1.0)	11 (1.7)
General hospitals (with psychiatric service)	28 (6.0)	32 (5.0)	53 (7.5)
Residential treatment centers	8 (1.7)	26 (4.0)	21 (3.4)
Veterans Administration	NA ---	NA ---	2 (0.3)
Community mental health centers	NA ---	(c) ---	8 (1.1)
Total inpatient	71	91	149
Total all facilities	470 (100.0)	669 (100.0)	719 (100.0)

SOURCE: 1966 data from Beatrice Rosen, Morton Kramer, Richard Redick, and Shirley Willner, *Utilization of Psychiatric Facilities by Children*, U.S. Department of Health, Education and Welfare, NIMH, Mental Health Statistics, Series B, No. 1, 1968.

1968 data from White House Conference on Children, *Profiles of Children*, 1971, p. 105, Table 50; and the National Health Education Committee, Inc., *What are the Facts About Mental Illness in the United States?*, New York, 1971.

1969 data came from Shirley Willner in telephone conversation of March 21, 1973.

^aData are computed for 0-18 only.

^bData are for 0-21..

^cCombines both in and outpatient care.

^dOutpatient only.

Estimates of the rates per 100,000 population for various age cohorts and sex receiving clinical outpatient care are given in Table 10.18. As a class of facilities, outpatient care accounts for two-thirds of the children receiving services. As contrasted with the rates for all ages, which doubled between 1959 and 1965, the totals for all children under 18 years of age did not increase as rapidly. Table 10.19 presents comparative information for rates of change of age cohorts of both sexes versus the totals for all ages and for the proportion of males to females in each cohort at the 1965 date. Note that the growth rate in number of children receiving Outpatient Psychiatric Clinic service is less than the growth rate for adults. Males consistently outnumber females among those who receive services by nearly two to one. Disregarding sex-linked causes of mental illness, this consistent overrepresentation should be investigated more thoroughly to determine whether sex discrimination in the identification and provision of services exists.¹⁹

Table 10.18

ESTIMATED NUMBER OF PATIENTS UNDER CARE AND TERMINATIONS PER
100,000 POPULATION,^a OUTPATIENT PSYCHIATRIC CLINICS:
1959, 1965, AND 1968

Year	Patients Under Care				Terminations			
	Total All Ages	Total Under 18 Years	Under 10 Years	10-17 Years	Total All Ages	Total Under 18 Years	Under 10 Years	10-17 Years
Both sexes								
1959	286.0	327.0	224.0	493.0	161.9	197.0	135.8	292.7
1965	561.6	538.1	347.4	805.1	281.1	294.0	189.8	439.7
Males								
1959	356.0	427.0	292.0	639.0	196.3	257.1	177.8	381.3
1965	644.4	703.9	472.0	1029.4	312.8	384.5	258.1	562.0
1968	---	---	---	---	---	---	348.0	748.0
Females								
1959	220.0	224.0	151.0	337.0	129.1	134.6	92.1	200.9
1965	483.5	366.7	218.2	574.0	251.2	200.3	119.0	313.8
1968	---	---	---	---	---	---	153.0	482.0

SOURCE: U.S. Department of Health, Education and Welfare, *Outpatient Psychiatric Clinics--Annual Statistical Report Data on Patients, 1959-1965*, Public Health Service, National Institute of Mental Health.

^aRates are computed on the basis of July 1 civilian population, U.S. Bureau of Census, Current Population Reports Series P-25.

We attempted to ascertain current total expenditures for outpatient services for mentally disturbed and mentally ill youth by several contacts with various NIMH personnel. We were unable to locate anyone there who was able to provide or knew

¹⁹ Two evaluations of institutions and current practices for the mentally ill must be noted and recommended: the first, D. L. Rosenhan, "On Being Sane in Insane Places," *Science*, Vol. 179, Jan. 19, 1973, pp. 250-258, for the graphic information it presents with respect to the classification and general powerlessness of the institutionalized mentally ill; and the second, P. H. Hoch and Joseph Zubin (eds.), *The Evaluation of Psychiatric Treatment*, Grune and Stratton, New York, 1964, for the excellent job it does of collecting into one place a variety of competent professional views on the difficult subject of psychiatric evaluation.

Table 10.19

COMPARISON OF CHILDREN RECEIVING SERVICES IN OUTPATIENT PSYCHIATRIC CLINICS BY SEX AND AGE COHORTS BETWEEN 1959 AND 1965

Age	Change Factor of Rate per 100,000 in Population	Male/Female Ratio
Total all ages	1.96	---
Under 18	1.64	1.91
Under 10	1.55	1.95
10-17	1.63	1.79

SOURCE: Derived from Table 10.18.

of good data on non-Federal expenditures. The most current data available were for 1971 for CMHCs, which are described in detail later in this section. We estimated total outpatient expenditures for mental health treatment of youth aged 0-21 to be approximately \$84 million, multiplying the total 1969 youth care episodes by the average estimated cost per episode for CMHCs in 1971. Data for 1968 for free standing outpatient clinics regarding operating expenditures per patient²⁰ are within 22 percent of the expenditure rate for CMHCs in 1971. Therefore our estimate of total outpatient services to mentally ill children is probably of the correct order of magnitude.

The American Association of Psychiatric Clinics for Children has made estimates of the sources of funds for these clinics.²¹ The cost of operating psychiatric clinics for children, the source of funds, and the difference in costs for the years 1955 and 1965 are shown in Table 10.20. Increased costs per clinic are general, and the greatest increase comes from government sources.

Information presented in Table 10.21 gives a view of the situation for the two-thirds of the youth served in outpatient psychiatric facilities, comparing various age cohorts according to primary diagnosis. Here again, the "Other" category is consistently the largest noted.

The concern for better and more detailed information is supported and elaborated on by Eveleen Rexford in these pointed comments.²²

As a nation we have not been able to look honestly at the scope of the problem of emotional disturbance in children and youth nor at the size and quality of the resources available to cope with these children. We have not developed the systematic surveys, the categories of conditions, the conceptual models, nor the adequate reporting and analyzing systems to know where we are.

However concerned we may be about the lacunae in our information regarding emotionally disturbed children identified by psychiatric facilities, the

²⁰ C. A. Taub, *Expenditures per Patient in Free Standing Outpatient Psychiatric Clinics—1968*, Statistical Note 22, Office of Program Planning and Evaluation, NIMH/HEW, April 1970.

²¹ As reported in J. W. Moss, *Background Paper on Special Programs for Handicapped Children and Youth for the 1970 White House Conference on Children and Youth*, U.S. Department of Health, Education and Welfare, December 1970. (Mimeo.)

²² Eveleen Rexford, as quoted in *Crisis in Child Mental Health*, pp. 257-258.

Table 10.20

DOLLAR VALUE FOR SOURCES OF FINANCIAL SUPPORT FOR A MEDIAN
PSYCHIATRIC CLINIC, 1955 AND 1965

Source of Funds	1955		1965	
	Percent	Amount	Percent	Amount
Fees	12	\$ 7,200	13	\$ 21,700
Community Chest, United Fund, etc.	31	18,600	14	23,600
Federal and state	26	15,600	44	74,300
Others	31	18,600	29	49,000
Total	100	\$60,000	100	\$168,600

SOURCE: American Association of Psychiatric Clinics for Children, *Children and Clinics*, Washington, D.C., 1968, p. 13 (as reported in J. W. Moss, *Background Paper on Special Programs for Handicapped Children and Youth for the 1970 White House Conference on Children and Youth*, U.S. Department of Health, Education and Welfare, December 1970, mimeo).

total situation may be far more serious. Many of the children residing in correctional institutions, welfare homes, state schools, and foster homes undoubtedly suffer from emotional and behavioral disturbances. They may be labeled dependent, neglected, delinquent, or retarded and there is no way under present circumstances to include them in a comprehensive mental health survey. Each grouping of institutions has its own nomenclature and its own programming. There are those who believe that the reform schools and correctional institutions of the country are the sites of the same neglect of mentally disturbed young individuals as the state hospitals' back wards were of adults.

Some Federal Programs for Mentally Retarded and Mentally Ill Children

Attaining reasonable services for mentally retarded and mentally ill children and youth depends delicately on knowing the size and composition of the afflicted populations and then providing and coordinating the appropriate services for those populations, including research, diagnosis, counseling, treatment, and other types of assistance. This objective is an admirable one, complicated and thwarted by sketchy demographic and expenditure information and by the multiplicity of existing programs.²³ Many of these have been discussed in previous sections. Here we concentrate on the National Institute of Mental Health, including the functions it provides in executing the Community Mental Health Centers Act, its research and training activities, and the operation of St. Elizabeths Hospital; on the Rehabilitation Services Administration's concern for the provision of services under the Developmental Disabilities Services and Construction Act; and on the roles played by the President's and Secretary's Committees on Mental Retardation.

²³ Secretary's Committee on Mental Retardation, *Mental Retardation Financial Assistance Programs*, U.S. Department of Health, Education and Welfare, July 1971, lists no less than 54 separate programs run by a variety of agencies having some relevance to mentally retarded individuals.

Table 10.21
ESTIMATED NUMBER OF TOTAL TERMINATIONS FROM OUTPATIENT PSYCHIATRIC CLINICS BY MENTAL DISORDER AND AGE, 1969

Diagnosis	All Ages	5	5-9	10-14	15-17	18-19	20-24	25-34	35-44	45-54	55-64	65-74	75+
Total	818,865	15,426	80,049	113,751	79,959	37,220	95,307	153,142	115,843	70,567	34,786	14,635	8180
Mental retardation	29,879	2,900	8,180	7,931	3,181	1,186	1,755	2,042	1,211	816	451	113	91
Organic brain syndromes associated with alcoholism	4,833	---	---	13	35	45	227	726	1,186	1,352	890	278	81
Organic brain syndromes associated with syphilis	552	---	13	82	20	7	13	53	57	84	138	52	33
Organic brain syndromes associated with drug or poison intoxication	2,770	2	20	94	371	357	765	486	283	182	123	52	35
Organic brain syndromes associated with cerebral arteriosclerosis and senile brain disease	5,388	---	3	5	4	2	5	35	61	229	1,002	2,165	1877
Other organic brain syndromes	16,746	904	3,598	2,552	981	474	1,141	1,664	1,488	1,386	1,234	762	562
Schizophrenia	100,784	480	1,717	2,897	3,880	4,331	14,333	27,158	23,381	14,189	6,000	1,777	641
Major affective disorders	12,519	7	13	25	69	70	443	1,045	2,043	3,834	3,466	1,218	286
Psychotic depressive reaction	5,470	6	23	85	141	128	477	1,021	1,185	1,001	847	390	166
Other psychoses	3,371	17	47	85	90	112	352	575	636	657	520	217	63
Depressive neuroses	70,340	89	507	1,967	2,584	2,854	10,626	19,504	14,682	9,467	5,410	1,983	667
Other neuroses	56,060	218	2,679	4,581	2,685	2,562	9,108	15,865	10,056	4,892	2,237	694	483
Personality disorders	124,455	420	4,914	13,769	12,996	7,281	22,192	31,441	18,980	8,608	2,477	840	537
Alcohol addiction	17,188	3	2	22	64	91	566	3,373	5,696	4,861	2,074	347	89
Drug dependence	7,558	---	2	122	648	867	2,127	2,134	1,013	401	152	65	27
Psychophysiological disorders	5,319	35	317	502	372	207	616	1,126	1,018	614	345	128	39
Transient situational disturbance and adjustment reaction to infancy	144,089	3,115	27,610	41,326	29,882	7,924	9,262	11,154	7,337	3,545	1,453	833	708
Other	211,544	7,230	30,404	37,693	22,014	8,722	21,299	33,740	25,530	14,429	5,967	2,721	1795

SOURCE: Unpublished data from the National Institute of Mental Health, HSMHA, as reported in the Mental Retardation Sourcebook of the Department of Health, Education and Welfare, DHEW Publication No. (OS) 73-81, September 1972, p. 91.

The National Institute of Mental Health. NIMH is responsible for seven distinct program areas that have some direct impact on handicapped children and youth: (1) Community Mental Health Centers, (2) Mental Health Research, (3) Hospital Improvement Grants, (4) Fellowships, (5) Training Grants, (6) St. Elizabeths Hospital, and (7) Scientific Communication and Public Education.

Community Mental Health Centers: In the last twenty years there has been a distinct trend to shift the locus of service delivery from residential institutions to the communities in which the served populations reside. This trend in mental health care has been accompanied by a considerable body of scholarship²⁴ and by several significant pieces of legislation.²⁵ In the latter case, NIMH has become a prime executor of provisions of the Mental Retardation Facilities and Community Mental Health Centers Construction Act,²⁶ whose multiple objectives are all aimed at creating a network of local centers for the distribution of mental health services. The Act provides for resources (1) to establish the initial operation of Community Mental Health Centers through a flexible grant mechanism to meet a portion of the costs of professional and technical personnel, (2) to provide a share of construction funds (one-third to two-thirds of costs and more if the site is located in a designated poverty area), and (3) to generally improve the organization and allocation of mental health services at the local level. Each of the centers created under this Act provides limited inpatient care, outpatient care, 24-hour emergency service, partial hospitalization, consultation, and some education. The guidelines under which NIMH is assisting states also stipulate that "centers are encouraged to develop rehabilitation services, training activities, and research and evaluation programs."²⁷ To accomplish these considerable objectives, a total of \$478.9 million has been expended for the program since its inception in 1965 to develop some 452 centers, of which 300 or so were in whole or part operational at the end of 1971.²⁸ In FY 1971, staffing grants totaled \$90.04 million. In FY 1972 staffing grants amounted to \$135.1 million and construction grants were estimated at \$9.8 million for FY 1973.²⁹ The Federal share ranges from 90 percent down to 45 percent, but typically in 1971 was on the order of 75 percent.

In 1971, services were being provided to about 797,000 individuals of all ages; in 1969 an estimate of the number of children and youth aged 0-21 was made

²⁴ The trend is documented earlier in this section.

Reasons often cited for this shift in service emphasis include the need to provide an alternative to hospitalization, provision of services to low income groups, and the need to integrate various forms of care at the local level; see H. G. Whittington, *Psychiatry in the American Community*, International Universities Press, New York, 1966, for the historical viewpoint and a setting of the context.

General literature reporting on selected aspects of the trend include: A. R. Foley et. al., *The Community Mental Health Center, An Analysis of Existing Models*, Joint Information Service, American Psychiatric Association, Washington, D.C., 1964; R. M. Glasscote et al., *Partial Hospitalization for the Mentally III: A Study of Programs*, Joint Information Service, American Psychiatric Association, Washington, D.C., 1969; and George James, "The Present Status and Future Development of Community Mental Health Research—A Critique from the Viewpoint of Community Health Agencies," *Annals of the New York Academy of Sciences*, Vol. 107, May 23, 1963.

²⁵ P.L. 88-164, P.L. 89-105, P.L. 90-31, P.L. 90-574, P.L. 91-211, P.L. 91-513, and P.L. 91-515.

²⁶ 42 U.S.C. 2681-2687.

²⁷ U.S. Department of Health, Education and Welfare, *Justifications of Appropriation Estimates for Committee on Appropriations, FY 1973*, Washington, D.C., 1972, Vol. 1, p. 40 (hereafter cited as *Justifications of Appropriation Estimates*).

²⁸ *Ibid.*

²⁹ Office of Manpower and Budget, *Catalog of Federal Domestic Assistance: Update to 1972*, Washington, D.C., 1972, p. 166. Continuity with Hill-Burton construction resources partially accounts for this rather small sum for construction.

indicating that 87,800 were being served including 7700 as inpatients and the remainder as outpatients.³⁰ While we are assured that the 1969 breakdown is the most recent available, it obviously does not reflect developments in the CMHC program over the last four years.³¹ Apparently there are no accurate answers to our straightforward questions, "How many children and youth were served in CMHCs in 1972, and what did it cost?"

Under a separate provision of the basic Act,³² some \$10.0 million was expended in FY 1972 for a Child Mental Health Program to stimulate innovative approaches expanding the range of services offered children through the CMHC vehicle. For that money, 32 separate projects were funded in FY 1973 for a variety of specific purposes, all of which are child-oriented.³³

HEW's Office of Child Development and NIMH have announced plans to integrate Headstart children into the facilities and services provided under the CMHCs. Emotionally disturbed, mentally retarded, and physically handicapped Headstart children (especially those in the first two categories) will be eligible.

Mental Health Research: It has only been in the last 15 to 20 years that scientific inquiry into the areas of child personality and behavior has progressed to the point where a distinct professional specialty is recognizable. The character and style of research programs sponsored by NIMH are as follows:

- Much of the work has been investigator initiated.
- Research interests have been richly diverse, and research attention has been diffuse and subject to periodic realignments as areas of specific interest waxed and waned.
- Child-centered (as contrasted with the generic, human-centered or even disease-specific) research has not been treated as a separate domain until quite recently, and then only as "add ons" to ongoing efforts.

Because child mental health is not yet a precisely defined specialty, it is very difficult to assign from among the total research program of NIMH particular proportions that are child-specific. Nonetheless, there are certain guidelines in the current budget and in previous investigations of this problem.

Mental Health Research Grants³⁴ amounted to a total of \$82.47 million in FY 1972 and were estimated at \$86.47 million in FY 1973.³⁵ About 1485 separate projects were funded (including 192 so-called "Small Grants" not exceeding \$5,000) to respond to the broad-scale objectives of creating new knowledge about human

³⁰ CMHC population data were provided by Ms. Shirley Willner, Biometry Division, NIMH, telephone conversation, March 21, 1973. See also Table 10.16, above.

³¹ A 1968 figure of 52,000 children and youth aged 0-18 has gained popular currency; see, for example, White House Conference on Children, *Profiles of Children*, p. 108, Table 50. The need for more timely data, however, particularly for as large and important a program as this, is underscored by the dated reference to the subject population contained in the FY 1973 Budget Justifications. See *Justifications of Appropriation Estimates*, p. 52: "In 1968, approximately . . . 52,000 [children] were patients in community health centers."

³² Community Mental Health Centers Act, Part F, Section 271.

³³ *Justifications of Appropriation Estimates*, p. 52.

³⁴ Public Health Service Act, 301 (d); P.L. 78-410.

³⁵ *Justifications of Appropriation Estimates*, pp. 20-25.

mental diseases, of doing clinical research, and of applying the results of this knowledge to actual mental health problems. NIMH's Divisions of Special Mental Health Problems and Extra-Mural Research Programs have primary responsibility for the child-specific portion of the overall research program. Four specific lines in the budget appear to pertain to children directly. The Early Child Care segment amounted to \$2 million in FY 1973, Crime and Delinquency added \$4.1 million, Child Mental Health Research (not to be confused with the Child Mental Health portion of Community Mental Health Centers) had \$1.5 million of the inclusive Mental Health Services line of \$9.089 million earmarked, and some portion of the \$2.18 million that was expended for Metropolitan Problems must have had an impact on children.³⁶ Fortunately, others have been concerned about the matter and have ventured estimates of the amount going for child-related work.

Reporting in early 1971, the Ad Hoc Committee on Child Mental Health made the observations that only \$10.23 million of the total \$77.75 million research budget for FY 1970 could be directly attributable to "Primary Child Mental Health Support." Even when the definitions were relaxed to include this as a secondary category of interest—i.e., the words "Child-Children" or "Adolescence-Adolescent" appeared somewhat less prominently in the project summary—the total increased to only \$14.23 million or some 18 percent of the total research budget.³⁷ The difficulty of assigning current proportions to child-related investigations was emphasized by various members of the pertinent NIMH staffs in interviews.³⁸ Assuming, for the sake of illustration, that the proportions reported by the Ad Hoc Committee have increased slightly to an even 15 percent for primary research and 20 percent for both primary and secondary combined (the increase would partly account for recently added marginal increments that are distinctly child-specific), this would mean that of the total FY 1972 expenditure of \$82.47 million for research grants, an estimated \$12.4 million and \$16.5 million were spent in each category, respectively.

A contrast is evident between these estimates and the stated goals of NIMH as reported in the current budget justifications: "Activities directed at improving the mental health of children carry the highest priority for NIMH."³⁹ Specific details were spelled out in the narrative describing Child Mental Health Research Programs in terms that would appear to apply across the board:

- Coordination of children's services, particularly at the level of the community mental health facility.
- Expansion of preventive programs, also via the community mental health center vehicle.
- Development of means to reduce hospitalization of children.
- Supporting mental health-oriented day care, nursery, and kindergarten programs.
- Improving referral services for minorities, emphasizing the community health center's role.

³⁶ *Catalog of Federal Domestic Assistance*, p. 170.

³⁷ Ad Hoc Committee on Child Mental Health, *Report to the Director—National Institute of Mental Health*, Department of Health, Education and Welfare, Public Health Service, Washington, D.C., 1971, pp. 25-26.

³⁸ We also queried the Scientific Information Exchange at the Smithsonian for project descriptions, but had little success with the cost issue because budgetary data are not supplied with project descriptions.

³⁹ *Justifications of Appropriation Estimates*, pp. 23-24.

- Creating special services for the adolescent dropout and drug user.

This is a large and admirably intentioned list of tasks. One must wonder just how far \$12.5 million or even \$16.5 million will go in beginning to satisfy it?

Hospital Improvement Grants: Designed to improve the care and treatment of the mentally ill in state hospitals, Mental Health Hospital Improvement Grants⁴⁰ are small, special purpose, and project-oriented. Projects average about \$83,000 (with a maximum annual grant of \$100,000 allowed over a period of ten years), and total support for the program was \$6.9 million in FY 1972 and FY 1973. All states but one have these grants, responsibility for which as of 1972 was transferred to the HEW Regional Offices.⁴¹ Some benefit accrues to handicapped children (the mentally ill and emotionally disturbed who are inpatients for the most part), but the amount is not measurable.

Mental Health Fellowships: A manpower training component of NIMH's multifaceted role is contained in the Mental Health Fellowship program, which in FY 1972 and FY 1973 was funded at a level of \$8.7 million.⁴² Two basic classes of award are made, research development for established professionals and fellowships for pre- and post-doctoral students. Of the 657 total awards made in FY 1973, 35 percent, or 230, were directly related to child mental health problems, and 29 were in other specialized areas having some relationship to children and youth.⁴³ A rough estimate of child-related fellowships, using simple proportions, would therefore be \$3.6 million.

Mental Health Training Grants: To cover a portion of the costs incurred by educational institutions in training mental health professionals in an assortment of fields, and to provide stipends to those receiving the training, the Training Grants program has been established and funded in FY 1973 at a level of \$96.35 million.⁴⁴ Of this total, Behavioral Sciences with \$24.28 million lead the fields, followed, in descending order of resources, by Psychiatry (\$20.473 million), Social Work (\$12.678 million), Experimental and Special (\$7.743 million), and Psychiatric Nursing (\$7.259 million). There is no information that would enable a breakdown by child-specific expenditures to be made; however, currently some preference has been given to those preparing for careers in child mental health.⁴⁵

St. Elizabeths Hospital: Organizationally placed within NIMH in 1969, St. Elizabeths Hospital provided treatment and rehabilitation services for some 3300 inpatients and 2650 outpatients of all ages in 1972. Through its Division of Clinical and Community Service, the hospital also operates a Community Mental Health Center for the southeast sector of Washington, D.C., and conducts mental health research and training programs. The total obligation in FY 1973 was estimated at \$55.86 million, of which the Federal share totaled \$28.27 million.⁴⁶

⁴⁰ Public Health Service Act, Section 303(a) (2). Section 303(a) (1), Mental Health—Hospital Staff Development Grants, is related.

⁴¹ Of the 302 eligible state mental hospitals, some 179 had received grants.

⁴² *Catalog of Federal Domestic Assistance*, pp. 169-170.

⁴³ *Justifications of Appropriation Estimates*, pp. 33-37. The Division of Manpower and Training Programs (Behavioral Sciences Training Branch) is the responsible section of NIMH.

⁴⁴ *Catalog of Federal Domestic Assistance: Update to 1972*, pp. 169-170.

⁴⁵ *Justifications of Appropriation Estimates*, p. 32. The Division of Manpower and Training Programs and a variety of its constituent branches have responsibility.

⁴⁶ *Justifications of Appropriation Estimates*, pp. 78-95, at pp. 81, 85. The balance of operating expenses is mainly obtained from "Non-Federal sources," i.e., receipts and reimbursements for care.

St. Elizabeths reflects the general trends to reduced inpatient loads, shorter median stays, and reduced median times since admission. Over 2000 individuals have been cut from the average annual inpatient caseload in the last several years; the median stay for all ages for those patients discharged in 1971 was three months (down from an eleven-month figure in 1967); and the median time spent since admission was, for those on the rolls at the end of 1971, 5.3 years (down from 9.5 years in 1967).⁴⁷

The number of children and youth served by St. Elizabeths is not large. Besides a children's ward with a 30-bed capacity, the bulk of the 0-24 age group is served in the Community Mental Health Center. In FY 1972, a total of 696 individuals aged 0-24 were served, but St. Elizabeths has made no breakdowns by inpatients and outpatients. Nor is it known what fraction of the total is accounted for in the CMHC contribution.⁴⁸ A special program devoted to the mental health of the deaf is a particularly interesting aspect of St. Elizabeths operation; it serves a select group, averaging about 47 persons of all ages.⁴⁹

Scientific Communications and Public Education: Funded at \$7.298 million in FY 1972 and FY 1973, this program operates both the National Clearinghouse for Mental Health Information (NCMHI) and the National Clearinghouse for Drug Abuse Information. The primary objective of the program is to provide public information about all mental health activities; hence it is responsible for literally thousands of pamphlets, brochures, articles, and other media. Its contribution to handicapped children is not estimable.

Developmental Disabilities. The Rehabilitation Services Administration of the Social and Rehabilitation Service has been given prime responsibility to administer the Developmental Disabilities Services and Facilities Construction Act.⁵⁰ We discuss this Act in terms of the definitions of "developmental disabilities" contained in it, its purposes, and its main programs, and provide a summary of a recently completed evaluation of the program.

The basic Act defines developmental disabilities in the following terms:

... a disability attributable to mental retardation, cerebral palsy, epilepsy, or another neurological condition of an individual found by the Secretary to be closely related to mental retardation or to require treatment similar to that required for mentally retarded individuals, which disability originates before such individual attains age eighteen, which has continued or can be expected to continue indefinitely, and which constitutes a substantial handicap to such individuals.⁵¹

Because the original Act does not identify other neurological handicapping conditions except mental retardation, cerebral palsy, and epilepsy, a number of requests to expand the number of eligible categories were made in 1971 and 1972, and the Secretary referred the matter to a study group for advice.⁵² A second, related difficul-

⁴⁷ *Ibid.*, p. 88.

⁴⁸ Data obtained in telephone conversation with Mrs. Lyles, Biometry Division, St. Elizabeths Hospital, March 22, 1973.

⁴⁹ *Justifications of Appropriation Estimates*, pp. 88-89.

⁵⁰ P.L. 91-517; 42 U.S.C. 2661. The Act dates from October 30, 1970, when it became a law.

⁵¹ *Guidelines for Services and Programs for Developmentally Disabled Persons*, U.S. Department of Health, Education and Welfare, Social and Rehabilitation Service, Rehabilitation Services Administration, Division of Developmental Disabilities, May 1972, p. 1. The appropriate legal source for the citation is 42 U.S.C. 2691, Title IV, Section 401 (1).

⁵² *Federal Register*, Vol. 37, No. 176, Sept. 9, 1972, p. 18424.

ty arose over the meaning of "substantial handicap," and this issue has been resolved in the following manner: "Services provided in a particular community *under this Act* will depend on the needs and existing resources of that community."⁵³

The Act is intended to provide services, facilities, and manpower training via three basic program mechanisms: (1) formula grants to states—for administration, planning, services, and construction, (2) service projects—hospital improvement, rehabilitation service projects, and initial staffing, and (3) university-affiliated facilities—concentrated mainly on the training of service and research personnel.⁵⁴

To accomplish these programs, some \$49.54 million was expended in FY 1972 and \$44.46 million was estimated for FY 1973.⁵⁵ However, these expenditure levels are well below the amounts authorized, which were \$105 million and \$130 million for the corresponding years.⁵⁶ This difference was noted in the 1972 *Secretary's Budget Memo*, "... and if the President's goals for mental retardation ... are to be reached, the appropriation must be significantly increased."⁵⁷ Nonetheless, FY 1972 expenditures were held to the \$49.54 million figure; of this total, \$21.715 million went for state formula grants, \$23.575 million for rehabilitation service projects, and \$4.250 million for university affiliated facilities.

State grants⁵⁸ are designed to help coordination and planning activities at the state level to improve the flexibility and responsiveness of services delivered to the developmentally disabled. As a result, State Planning and Advisory Councils are required, as is a National Advisory Council on Services and Facilities for the Developmentally Disabled. Evaluation money at the rate of 1.0 percent of this program, or about \$200,000 in FY 1972, is likewise required. It was estimated that 43,000 were served in FY 1972.⁵⁹ Most state grants were in the \$400,000 range, but three states exceeded the million-dollar mark—California (\$1.387 million), Pennsylvania (\$1.115 million), and Texas (\$1.067 million).⁶⁰

Service projects, which are also matched,⁶¹ included \$10.075 million for initial staffing, \$7.0 million for service projects, and \$6.5 million for hospital improvements in FY 1972,⁶² a year in which some 132,000 persons were served and around 10,000 received training under these projects.⁶³

University affiliated facilities included 34 centers, whose "core" support was partly financed, and stressed demonstrations and interdisciplinary training for professionals to serve the developmentally disabled. The average grant was around

⁵³ *Guidelines for Services and Programs for Developmentally Disabled Persons*, p. 2.

⁵⁴ *Justifications of Appropriation Estimates*, Vol. VI, "Social and Rehabilitation Service," p. 163.

⁵⁵ *Ibid.*

⁵⁶ P.L. 91-517, Title I, Part C, Section 131, "Authorization of Appropriations."

⁵⁷ *Secretary's Budget Memo*, Office of the Secretary, Department of Health, Education and Welfare, Washington, D.C., March 1972, p. 17. (Mimeo.)

⁵⁸ The Federal share of the match for services was 75 percent in FY 1972, 70 percent in FY 1973, and up to 90 percent for areas designated as poverty areas by the Secretary. For construction projects, the range was up to two-thirds for regular grants and up to 90 percent for poverty areas.

⁵⁹ *Justifications of Appropriation Estimates*, Vol. VI, p. 122.

⁶⁰ The top three state recipients were closely followed by Ohio (\$937,000), Illinois (\$851,000), and Michigan (\$768,000). *Justifications of Appropriation Estimates*, Vol. VI, pp. 172-173.

⁶¹ The Federal share ranges between 66 and 90 percent, but averages somewhere around 75 percent for the 670 separate projects funded in FY 1972.

⁶² *Catalog of Federal Domestic Assistance*, p. 341.

⁶³ *Justifications of Appropriation Estimates*, Vol. VI, p. 126.

\$125,000/year/center, and it has been estimated that 15,000 received some training in FY 1972.⁶⁴

Developmental disabilities is best regarded as a supplemental program aimed specifically at a difficult subset of the handicapped population that often has been slighted or for which more detailed planning and orchestrating of available services and resources were needed at the state and local levels. The total estimated number served in FY 1972 is approximately 175,000, some considerable proportion of which is children and youth aged 0-21. The total of Federal and matching resources expended was on the order of \$66.0 million in FY 1972.⁶⁵

While a full-scale review of this program is beyond the scope of this report, others have recently begun the assessment task in depth.⁶⁶ On reading the Larson-Weichers evaluation, one is struck with the image that the Developmental Disabilities program is but one more colored chip in the kaleidoscope of Federal programs for the handicapped. Problems with standards, coordination, basic definitional issues, and hence data are very much at the forefront of the evaluators' attention. Coordination between levels of government and within the individual states—a major objective of the program—is noted as a chronic problem. Other problems mentioned by Larson and Weichers include inadequate Federal leadership to establish program goals, poor control apparatus, and weak technical assistance; lack of money; lack of local capacity to care for the served population; inability of established state advisory councils to provide effective leadership; short-term funding with the resultant lack of continuity and planning; and lack of analyses and evaluations of program effectiveness.

President's and Secretary's Committees on Mental Retardation. Two important groups are constituted to provide both policy and program assistance and expertise at the highest levels of the Executive Branch.⁶⁷ These committees make significant contributions in the areas of increasing public awareness, coordinating governmental units serving the mentally retarded, and evaluating operations from a strategic perspective. Perhaps the most subtle contribution of each committee is the fact that it is compelled to view the whole spectrum of services provided to an identified target population from a comprehensive point of view—a rare and heroic undertaking given the complicated and ponderous nature of the overall system.

For the \$550,000 expended on the President's Committee in FY 1972,⁶⁸ a variety of policy studies and papers were produced of the kind characterized by earlier,

⁶⁴ Ibid., pp. 127-128. Construction authorized under this segment of the Act was being phased out in FY 1972 and accounted for only \$31,000 of the \$4.281 million actually expended here; no construction funds were budgeted in FY 1973.

⁶⁵ We are unable to find hard information on how many aged 0-21 are in fact served under this program. Richard Walker, statistician in Program Evaluation, Division of Developmental Disabilities, Rehabilitation Services Administration, indicated to us that these data are "not available." (Telephone conversation, March 23, 1973.) Lacking some reliable information from those responsible for the program, we have made an arbitrary estimate that half of the 175,000 total were aged 0-21, and that half of the \$66.0 million gross expenditure for both Federal and matching sources benefited children too. We prefer not to make arbitrary estimates, but the current state of the data makes it necessary.

⁶⁶ C. W. Larson and J. Weichers, *Survey of Operation of the Developmental Disabilities Services and Facilities Construction Act of 1970 (P.L. 91-517) in States*, Department of Health, Education and Welfare, Rehabilitation Services Administration, October 31, 1972 (study document).

⁶⁷ The President's Committee is authorized under Executive Order 11280, May 11, 1966.

⁶⁸ As noted in Table 10.4 above; see also *Catalog of Federal Domestic Assistance*, p. 698, for a fuller description of activities.

much read efforts such as *MR 69: Toward Progress: The Story of a Decade* and *MR 70: The Decisive Decade*.⁶⁹

An attempt to estimate and integrate all Department of Health, Education and Welfare expenditures for the mentally retarded was made by the Secretary's Committee on Mental Retardation in 1971.⁷⁰ While the effort was only partly successful, the perspective taken—i.e., comprehensive for a target population—was quite insight provoking. The coordination, fragmentation, and information deficiencies that we frequently note throughout this report were obvious in the Committee's 1971 report as well; \$110,000 was expended on the Committee in FY 1972.⁷¹

PROBLEMS CITED BY MENTAL HEALTH ADMINISTRATORS

Thirty-two states responded to our survey of mental health agencies with descriptive material on their programs. Of those, half volunteered information on problems they face in providing services to mentally handicapped youth. As with other agencies we surveyed, the inadequacy of present funding levels was the problem most frequently cited. Other areas of concern to several states were the lack of coordination among programs; the need for more program data, planning, and evaluation; and the need for more community based facilities. A summary of the problems cited is contained in Table 10.22.

Insufficiency of Funds

Lack of resources was the problem cited most often, and typically in two ways: (1) funds generally are not available to serve all those with a need, and (2) funds for specific subsets of the mentally handicapped, or funds for specific types of facilities, are especially lacking. For example, after officials in Massachusetts indicated the general problem of funds, one went on to say:

The greatest problem area, to my knowledge, consists of two kinds of multi-handicapped people. The first is multi-handicapped, profoundly or severely retarded babies for whom this Commonwealth has too few resources. The State Schools are over-crowded, with long waiting lists and there are only two private nurseries which can take care of these babies. Both nurseries, of course, are always full even though they have expanded over the last few years.

The second group of people needing and lacking resources are the emotionally disturbed retarded who seem to fall between resources geared to treating only emotional problems or only retardation problems.

Coordination of Various Programs

Coordination has been cited as a problem many times by officials in a variety

⁶⁹ Both documents are available from the Government Printing Office.

⁷⁰ Secretary's Committee on Mental Retardation, *Mental Retardation Activities of the Department of Health, Education, and Welfare*, Department of Health, Education and Welfare, Washington, D.C., January 1971.

⁷¹ Table 10.4 above.

Table 10.22

PROBLEMS CITED IN SURVEY RESPONSES BY STATE MENTAL HEALTH PROGRAM ADMINISTRATORS

State Responding	FUNDS					PROGRAM PERFORMANCE													
	Inadequate Resources Committed	Low-Population/Large-Area States Need Proportionally More Funds	Need Greater Flexibility in Use of Funds	Need Cooperative Funding for Multi-Agency Applications	Need Advance Knowledge to Ask for Matching Funds	Slow Development of Guidelines	Need More Service for Adolescents	Need More Service for Preschoolers	Need Coordination Among Programs	Need More Planning and Evaluation	Lack of Data	Shortage of Personnel	Shortage of Facilities	Need for Child Advocacy	Should Provide Family Assistance	Rural Areas Need More Service	Inadequate Career Opportunities and Preparation	Need More Community Facilities	Severely- and Multihandicapped Need Better Service
Alabama	●																		
Arkansas	●					●													
California	●										●	●			●		●	●	
Georgia	●		●																
Hawaii	●																		
Illinois	●									●									
Indiana	●							●	●	●						●			
Massachusetts ..	●						●	●	●		●						●	●	
Missouri	●		●	●					●				●	●					
New York	●												●	●					
North Dakota ...	●										●								
Oregon	●							●	●	●									
Rhode Island ...	●					●													
Texas	●						●	●	●								●		
West Virginia ..	●				●														
Wyoming	●	●			●						●	●			●		●		
Total	12	1	2	1	1	1	2	1	4	4	2	3	3	2	1	2	1	5	2
Total	17					33													

of agencies, but it is perhaps best summarized by the response we received from the Texas Mental Health Mental Retardation Agency:

One of the most pressing and difficult issues in Texas and other areas may be termed as a lack of effective and integrated service delivery systems for persons with mental health, mental retardation and related problems. . . . To make matters worse, these often become conflicting and competitive. . . . As a result, the intended client receives inadequate service or no service at all. Such a condition also has a geographic dimension, as competing systems often do not follow a systematic and orderly growth plan, thereby concentrating services in certain areas at the expense of other areas.

Data, Planning, and Evaluation

Many of those responding to but not completing our survey indicated they would like to assist the study but that they did not have the information on services to youth that we requested. Oregon pointedly tied the lack of service coordination with insufficient planning:

Funds must be assigned for planning purposes; the present attitude which prevails is that money spent on planning takes away from services. Without sufficient money available for planning, fragmentation is certain to continue.

A Major Issue Surfacing and Searching Resolution

The closure of mental hospitals was a central issue in three of the states that we visited (California, Massachusetts, and Illinois). It appears to be a major issue that will not be easily resolved. We signal it as an area requiring particular analytic attention in the coming years and one which is particularly deserving of coordination and research at the Federal level.

While the issues are complex, the general trend to reduce the size of state mental health residential facilities seems well established. This decision is often taken for a variety of reasons, and hastened to reduce overstressed state budgets. However, there is some question whether such moves result in less costly, or merely less visible, outcomes. In California, for example, two pieces of legislation designed to provide an alternative to the state mental hospitals have had the effect of inducing closure and a rapid egress of patients from these facilities. The so-called "Short-Doyle" program has turned out to be more of a replacement than an alternative to the state hospitals, as shown in the summary accounts in Table 10.23. While the issues are too complex for detailed analysis in this report, we recommend that the cited literature is a reasonable place to begin appreciating the multiple implications of this surfacing trend.⁷²

⁷² ENKI Corporation, *A Study of California's New Mental Health Law*, Chatsworth, Calif., 1972; California State Assembly, Interim Committee on Ways and Means, Subcommittee on Mental Health Services, *The Dilemma of Mental Health Commitments in California*, 1966; Department of Mental Hygiene, State of California, *The New California Mental Health Act*, 1969; State of California, Welfare and Institutions Code, Division 5, Section 5001; S. Steven Rosner, "The Rights of Mental Patients—The New Massachusetts Law," *Mental Hygiene*, Winter 1970, pp. 117-119.

Table 10.23

CALIFORNIA STATE MENTAL HEALTH BUDGET

Fiscal Year	Local Programs (Short-Doyle)	State Hospitals for Mentally Ill	Total Budget for Direct Services	Local Program Total (%)
1966-1967	\$ 18,600,733	\$116,743,640	\$135,344,373	15.9
1967-1968	23,901,030	111,997,251	135,888,281	21.4
1968-1969	27,500,000	111,860,999	139,360,999	24.6
1969-1970	53,387,173	112,786,924	166,174,097	32.1
1970-1971	72,436,000	109,928,921	182,364,921	39.1
1971-1972	104,140,684	107,307,958	211,448,642	49.2

SOURCE: *A Study of California's New Mental Health Law*, ENKI Corporation, Chatsworth, California, 1972, pp. 48-50.

PART 3
NEXT STEPS IN THE RESEARCH

This part briefly discusses our next report—the evaluation of programs for the auditorially and the visually impaired youth.

11. FUTURE ANALYSIS

POLICY ISSUES AND OPTIONS: RESEARCH APPROACH

This report focuses on existing Federal and state programs serving all types of mentally or physically handicapped youth, and our descriptive overview of those programs and many of their problems. Our next report will focus more narrowly on auditorially and visually handicapped youth, using information from this report and other sources to analyze alternative future Federal policies for improving services to them.

Our basic research approach is policy-analytic, as described in Sec. 1. In the next phase of this research, we shall take a comprehensive look at current and prospective programs and policies aimed at the target population of sensorially handicapped youth. Our evaluation effort will concentrate on alternative policies to alleviate the identified problems and on the Federal role as it relates to those recommended policies. Evaluating each alternative policy demands a multi-method research approach: no single methodology will suffice.

Our evaluation framework is based on 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 criteria will form the basis of a "scorecard" for evaluation and comparison of alternative future government policies. Six basic questions shape our research approach:

- What are the *problems* in the present system of government programs for service to youth with hearing or vision handicaps, and what are their service *needs*? We have discussed the present (benchmark) system and its problems. The next report will further describe these and other problems and service needs as they concern sensorially impaired youth.
- What are the *objectives* of various participants in the system? Section 4 discusses the diverse objectives of the handicapped population, individual government officials, specific agency programs, and "society." Our next report will contain survey results on the specific goals and objectives of families with sensorially impaired youth.
- What *criteria* are useful in evaluating and comparing policy options in terms of different objectives? The last part of this report discusses the set we plan to

- utilize, including measures of current resource consumption, equity, future economic effects, and effects on the quality of life of the handicapped individual.
- What *policy options* exist for improving services and alleviating the current system's problems? In addition to the base case option of not changing the present system, the following illustrate groups of policy issues and options that may be considered:
 - A system of locally or regionally based centers providing comprehensive needs-assessment, diagnosis, direction, and periodic needs-reevaluation services each youth.
 - Readjustment of the mix of services delivered, increasing the provision of underdeveloped but effective services.
 - Emphasis on a prevention strategy for particular etiologies.
 - Emphasis on early identification and service strategy for youth with certain types and degrees of handicaps.
 - Emphasis on (1) vocational rehabilitation strategy, or (2) on an income maintenance strategy for certain subpopulations of the handicapped.
 - Emphasis on (1) quality services to relatively few, e.g., the severely handicapped or those most able to benefit from service, or (2) minimal services to many.
 - Adoption of incentives to reduce the geographic and age inequities in service delivery.
 - Provision of sufficient resources to meet the service needs of *all* sensorially impaired youth.
 - A potentially feasible increase in resources, e.g., 50 percent.
 - Changes in the institutional structure at the Federal level, without increased resources.
 - An improved Federal role in data collection and program effectiveness evaluation.
 - A Federal role in a program area patterned after one of the Catalytic, Special Revenue Sharing-Plus, Controllership, Direct Operation or other characteristic models.
 - What are the *implications* (in terms mainly of costs and effects) of adopting each different policy option? Recommended criteria will be utilized to the extent that data permit in evaluating each policy option and, as appropriate, analyses will be conducted separately for various subpopulations of sensorially impaired youth. Where reliable data are not available, we will depend on more subjective data or on professional expert opinion to measure effects. We plan to use a variety of methods for obtaining information on criteria for policy options. For example, a cost model will be developed to assess resource criteria, to indicate the impacts on various sources of funds, and to estimate costs over the lifetime of handicapped youth. Economic criteria will be assessed using benefit-cost techniques. Impacts on the handicapped person's quality of life will depend on methods of estimating the number of persons with various degrees of sensory impairment and nondependency and on eliciting participant preferences; about 100 families with sensorially impaired youth will be queried. Where project staff members lack expertise, such as in making assessments about various medical

treatment outcomes, we will rely on expert consultants. For example, the impact of a medical prevention strategy on the cost, size, and dependency of the handicapped population can be assessed by using the costs and probabilities of success of various medical preventive services, a lifetime benefit-cost model, and various estimation techniques. Not all options will merit full analysis. Some will be shown to be clearly inferior after making only "back-of-the-envelope" calculations; others will be analyzed but, for assorted reasons, may not become recommendations in our next report; and others, the most promising, will be analyzed with respect to the various roles HEW might fulfill in creating a better service system. Section 3 of this report elaborates on the policy process and serves as a key structural reference for these recommendations, i.e., where should what kinds of adjustments be made by whom?

- Which of the analyzed policy options should be implemented at the Federal level, and *what role should HEW play?* These are questions best answered by HEW and other Federal officials, but this study will present policy options, evaluated as well as possible in terms of the various criteria, and discuss the relative merits of each. Periodically while preparing our final report, which will be an assimilation of findings about the analyzed policy options, we plan to issue supplementary notes about each of the individual options.

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. Auditorially and visually handicapped youth have been selected at HEW's request because (1) their handicaps are more readily identified and classified, (2) their handicaps can severely affect every aspect of their lives, (3) a wide range of services and programs already exist for them with varying effectiveness, (4) the data appeared more readily available for these handicaps, and (5) the program objectives, effectiveness, and benefits appeared more easily assessable than those for other handicapping conditions such as emotional disturbance.

To reiterate, 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. Because this is an overview study utilizing available data, it cannot answer all questions, but it does generate a good deal of new information and perspective.

CRITERIA: MEASURING PERFORMANCE

The evaluation criteria we intend to use are designed to show major policy effects, yet they are small enough in number to be manageable. Specific criteria should permit comprehensive evaluation, yet be as measurable as possible on each of four objective dimensions, discussed below: current resource consumption, equity, future economic effects, and effects on the individual handicapped person. 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. To compare the different effects of various services and policies, we have attempted to select criteria that can be used as common denominators. Because the needs and

ability to benefit from services differ for various handicapped subpopulations, these criteria must be applied separately for each subpopulation and for each service whenever feasible. Subpopulations are defined by such factors as age, degree and type of handicap, socio-economic status, and geography. Typical questions that might be raised are, how successful are alternative policies for meeting the needs of the handicapped? And how many resources do various policies consume?

These criteria will be refined and supplemented as necessary. The lack of data is, as usual, the greatest deterrent to evaluating programs for handicapped youth; consequently, it may not always be possible to use the criteria exactly as presented here, and in such cases, we shall attempt to construct and use indirect or proxy measures. Assessments of data quality and availability are presented in earlier sections of this report.

Criteria of Current Resource Consumption. Although resource consumption could be measured strictly in *dollar terms*, we also consider *facilities* and *personnel* because of their long lead times. In analyzing finances, we attempt to specify both total annual expenditures for a program and the cost per youth served. Disaggregation of data by service and subpopulation is important to understand whose resources are being tapped (e.g., Federal, state, the handicapped person, and his family) to serve which segments of the handicapped population, and to be able to weigh service effects against costs.

Criteria of Equity. To measure how "fairly" a service is distributed among various subpopulations and to measure unmet needs, we consider *whether and how much of a needed service* the individuals in each subpopulation receive. Because each individual's needs and abilities to benefit from each service differ, equity does not mean that equivalent amounts of each service are necessarily provided each individual. Rather, equity involves two types of criteria: the percentage of the subpopulation needing service that actually receive it; and the variance among subpopulations in the quantity of services received. If satisfactory data are not available on service effectiveness, however, service quantity measures are sometimes used as proxies for the more desirable output measures. For example, the effectiveness of prevention programs is commonly assessed by counting the number of people immunized against a potentially handicapping disease.

Criteria of Economic Effects. We consider three criteria of economic effects (of service provision) on both the individual and various governmental levels by asking questions such as the following whenever possible: What is the expected net change in the present value of *expenditures for all future government assistance* to the handicapped person throughout his lifetime? For income maintenance? For all other services? What is the expected net change in the present value of the handicapped person's *future earnings*? And what is the expected net change in the present value of *future taxes* to be paid over the handicapped person's lifetime?

Criteria of Effects on the Handicapped Person. In addition to economic effects, other important humanitarian service benefits are considered. Services may influence characteristics of the handicapped population in the following ways, which translate into four types of criteria:

1. Number of persons with various degrees of sensory ability:¹
 - a. Blind
 - b. Partially-sighted
 - c. Deaf
 - d. Hard of hearing
 - e. Both a hearing and a vision handicap
 - f. Normal hearing and vision

2. Number of persons with various degrees of personal nondependence:²
 - a. Self-care
 - b. Family care—care within family
 - c. Community-based care—care provided by agencies such as foster homes or halfway houses
 - d. Confined care—care in institutions such as hospitals or long-term nursing homes

3. Number of persons with various degrees of economic nondependence
 - a. Earnings and property income, including private insurance, investments and pensions
 - b. Work-related transfer payments, including social insurance
 - c. Income-conditioned transfer payments

4. Attitude of handicapped youths' families on their post-service overall quality of life:
 - a. Harmful effect on quality of life
 - b. No effect
 - c. Slightly beneficial effect
 - d. Beneficial effect
 - e. Very beneficial effect

Considering the variety of possible program effects, one must use multiple criteria to evaluate policy alternatives. Real choices are so complex that consolidating a set of criteria into one overall effectiveness measure is both inappropriate and misleading.

Viewing all criteria for a single policy provides a good overview of the costs and effects of that policy; looking at a single criterion for several alternative policies enables one to compare and contrast alternative policies by that one measure. In general, however, the policy that is best by one measure will not necessarily be best by another. This highlights a difficult methodological problem: How is one criterion weighed against another in arriving at recommendations? Multidimensional preference theory is insufficiently developed to provide a general solution; consequently, trade-offs among alternative policies on various criteria must be made on a case-by-case basis. Still, the normal process of making value judgments in decisionmaking is enhanced by making objectives, criteria, and trade-offs explicit rather than by ignoring or considering them only implicitly. Data on some of these criteria are

¹ More detailed scales of function ability will be used when appropriate and feasible.

² Scales of nondependence used are those specified in Secretary of Health, Education and Welfare, *Planning Guidance Memorandum—1972*, February 15, 1972.

highly subjective; however, our approach is to try to incorporate all important factors explicitly, rather than including only those for which quantitative measures are available.

Criteria Relevant to Only One Type of Service. Until now we have discussed criteria appropriately used to evaluate a variety of services. Criteria in the following list are each relevant to only one type of service, and because they are, they do not permit comprehensive service evaluation and hence shall be used in a supplementary fashion. For each criterion presented in Table 11.1, it is implicit that whenever possible a comparison would be made between data for persons receiving a service and those not receiving it.

Table 11.1

SINGLE SERVICE EVALUATION CRITERIA

Type of Assistance/Service	Criteria
Prevention of handicapping conditions	Number of persons per 100,000 population initially acquiring each type handicap as compared with a base year.
Identification	Percentage of the handicapped population individually identified by the service system.
Direction	Percentage of those identified who are receiving a preferred mix of services.
Medical or surgical treatment	Probability of various changes in degree of handicap.
Income maintenance	Percentage of handicapped whose family income is above each of a set of specified levels.
Education	Average levels of various types of achievement.
Specialized training	Percentage of trainees achieving various levels of functional ability (e.g., in mobility, speech, use of appropriate sensory aids, activities of daily living).
Vocational training	Percentage of trainees continuously employed for at least 30 days following completion of training.
Job placement	Percentage of unemployed handicapped persons successfully placed.

Appendix A

PREVALENCE ESTIMATES AND DEFINITIONS OF HANDICAPPING CONDITIONS

This appendix has a dual purpose: to define in more detail the various handicapping conditions that are used throughout the report; and to review various estimates of the prevalence of handicapping conditions. Our prime observations are that (1) definitions presently used in the service system are not the same across various agencies, if the agency defines the handicap at all; (2) the stated definitions are almost never clear; and (3) reliable data on prevalence are generally not available, which results in divergent estimates by different services.

From the standpoint of this HEW-sponsored research, handicapped youth broadly include those with a significant physical or mental impairment that results 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. Types of handicapped youth included are those generally called visually or auditorially or speech impaired, crippled or other health impaired, mentally retarded, emotionally disturbed, or learning disabled. Types not included are those whose problems tend to be imposed by conditions in society, rather than by a physical or mental disability, viz., the "disadvantaged" youth.

Estimates of the number of handicapped youth vary widely depending on the definition used, the data believed, and the type of service needed. While we are not fully satisfied with the reliability of the estimates we present in Table A1, we are confident that they represent the correct order of magnitude of those requiring at least some of the special services described in this report. These estimates are plausible and widely used, but some of the other estimates discussed in this appendix have the same attributes. The definitions used for each handicap are specified as precisely as they can be later. Note that of the 83.8 million aged 0 to 21 youth in the United States in 1970, over 9 million are handicapped. Even taking into account the difficulties of making precise estimates without a comprehensive census of the handicapped population, the figures indicate clearly the tragic proportions of the problem.

Not a great deal of effort in this appendix is directed toward finding the "best" single definition of a handicapping condition, since we believe that a single definition of a handicap for every type of service is inappropriate. Our objective here is to discuss the commonly used definitions. First, handicapping conditions usually have

Table A1

ESTIMATED NUMBER OF HANDICAPPED YOUTH AGED 0-21 IN 1970

Type of Handicap	Number of Youth	
Visual impairment		193,000
Partially sighted	180,000	
Legally blind ^a	45,000	
Hearing impairment		490,000
Deaf	50,000	
Hard of hearing	440,000	
Speech impairment		2,200,000
Crippling or other health impairment		1,676,000
Mental retardation		2,800,000
Emotional disturbance		1,500,000
Learning disability		740,000
Multihandicapped		50,000
Total		9,550,000

^aIncluding 32,000 partially sighted.

multiple dimensions. A person may be handicapped in one dimension and not in another. For example, the usual definition for being legally blind 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. Therefore, many of the legally blind will have the capability to see things close up such as books, and hence are not really "blind" for many of the important functions of everyday life. From a standpoint of service policy, which this report deals with, the definition of handicap for eligibility for service ideally should be based on need or functional capability as well as ability to benefit from the service. Thus, the definition of handicap used should depend on the type of service to be given. Operationally, this means that a set of definitions is needed for each type of handicap, rather than a single definition. This is true even if one can describe functional capability in terms of degree of physical limitation.

Given that one wants to measure the severity of a handicapping condition, another problem is where to draw the line between the handicapped and normal populations. In defining the mentally retarded, for example, an IQ of 75 or below is sometimes used to distinguish the mentally retarded from the normal population. It is not clear, however, why a child with an IQ of 74 needs different educational services, for example, than a child with an IQ of 80. With mental retardation as with all other handicaps there is a continuum in the degree of the severity of a handicap, and the handicap can be measured on different dimensions (e.g., IQ and adaptive behavior for the mentally retarded). Definitions that are one-dimensional and purely binary in nature—the child is either handicapped or he is not—are very blunt and inadequate instruments for measuring a handicapped child's need for service.

Finally, the severity of a handicapping condition depends upon the environment in which the child and later the adult finds himself. That is, whether or not you need services depends on your functional needs. The loss of a leg may not be a significant handicap in the classroom, but may be in many job situations calling for physical activity. Therefore, a child may not be handicapped in the eyes of the

educator, but could be handicapped as viewed by the vocational rehabilitation counselor.

Because of these difficulties in developing definitions, we delineate our assumptions about the handicapping condition and its prevalence so that those who disagree can alter our estimates to arrive at their own conclusions. Table A2 gives some different estimates of prevalence in youth of various handicapping conditions. The most noticeable characteristic of these estimates is the wide variation among sources; the high estimate differs from the low estimate by a factor of 6. The differences noted are partially due to varying definitions used. Those differences and breakdowns within the categories of impairment (e.g., hard of hearing versus deaf) will be discussed in following subsections. Note that two of the estimates indicate a very small fraction are multiply handicapped, implying a small amount of double counting in some of the other estimates.

In interpreting estimates of the percentage of the handicapped population served by various government programs, one should keep in mind the uncertainty about the size of that population. Any conclusions must be tempered by the quality of information in this area.¹ It was not within the scope of this study to analyze the relative merits of each set of estimates. We do note that the relatively recent (1970) estimates of prevalence used by the Bureau of Education for the Handicapped (column b) are comprehensive, were made after a review of multiple studies of incidence, and have received wide usage.

This appendix takes up each handicapping condition in the order listed in Table A1, and discusses its definition and the estimates of its prevalence. We discuss the first impairment in greatest detail, since the various types of definition and estimation problems are common to most other impairments and need not be discussed repeatedly.

VISUAL IMPAIRMENT

Data on the incidence of visual impairment in youth are probably the best among the various disabilities. This stems from several factors: visual impairment is relatively easy to detect, a standard measure of "legal blindness" exists, and more widespread screening is done for it than for most other handicaps. The dichotomous definition of legal blindness does not allow the separation of the various functional capabilities among the visually impaired, and it stands to reason that services should not be the same for all those categorized as "blind." In fact, many of the legally blind are not and do not consider themselves blind, and services that are directed at the totally blind will not train the person who has residual vision to use that vision to best advantage. Therefore, a definition such as that for legal blindness gives some indication of who needs service, but is not sufficiently refined to indicate the type of service required, and does not include all those needing service. For much

¹ More research is needed and is being undertaken in this area, such as the extensive survey described in Sec. 5 being undertaken by Professor S. Z. Nagi of Ohio State University. His work attempts to ascertain not only health status but also the amount and type of government service an individual is receiving. This study, however, will only cover adults 18 years of age and over.

Table A2

ESTIMATES OF THE PREVALENCE OF HANDICAPPING CONDITIONS IN YOUTH
(In percent of total youth population)

Handicap	Estimate										
	(a)	(b)	(c)	(d)	(e)	(f)	(g)	(h)	(i)	(j)	(k)
Mentally retarded	2.300	2.300	1.480	2.25	6.30	7.000	---	---	1.54	---	---
Auditorial impairment	0.575	0.575	0.080	2.10	1.00	0.203	0.95	---	0.10	---	0.585
Speech impairment	3.500	3.500	2.400	5.00	4.50	1.300	1.30	---	3.60	---	5.000
Visual impairment	0.090	0.100	0.020	0.08	0.35	0.200	0.06	0.057	0.05	0.054	---
Emotionally disturbed	2.000	2.000	0.050	3.00	5.00	2.600	---	---	2.00	---	---
Crippled	1.000	0.500	0.028	0.50	0.35	0.180	---	---	0.21	---	---
Learning disabled	---	1.000	0.026	5.00	7.00	2.200	---	---	1.12	---	---
Other health impairment	1.000	(1)	---	0.50	---	0.050	---	---	(1)	---	---
Multihandicapped	---	0.060	---	---	---	---	---	---	0.07	---	---
Total	10.465	10.035	4.080	18.43	24.50	13.730	---	---	8.69	---	---

^aR. P. Mackie, H. Williams, and P. P. Hunter, *Statistics of Special Education for Exceptional Children and Youth, 1957-1958*, USOE Bulletin No. OE-35048-58, 1963, as reported in R. A. Rossmiller, J. A. Hale, and L. E. Frohreich, *Educational Programs for Exceptional Children: Resource Configurations and Costs*, National Educational Finance Project, Special Study No. 2, Department of Educational Administration, University of Wisconsin, Madison, Wisconsin, August 1970.

^bEstimated for age 5-19 youth in 1969. U.S. Department of Health, Education and Welfare, *Handicapped Children in the U.S. and Special Education Personnel Required--1968-1969 (est.)*, Bureau of Education for the Handicapped, August 1970.

^cEstimate developed from information contained in *1969-80 Summary of Special Education Services of Bureau for Special Education*, Division for Handicapped Children, Wisconsin Department of Public Instruction, 1970 (mimeo) as reported in Rossmiller, op. cit., p. 122.

^dEstimates developed by the North Dakota State Department of Public Instruction as reported in *Description of Special Education Program 1972-1973*, submitted to the Bureau of Education for the Handicapped.

^eEstimates developed by the Nebraska State Department of Education as reported in *Description of Special Education Program 1972-1973*, submitted to the Bureau of Education for the Handicapped.

^fActual number of children in Alabama identified as needing special education service through teacher referral divided by the number of children 5-17 according to the 1970 U.S. Census. The number of identified children is taken from *Alabama Five-Year Plan Program for Exceptional Children and Youth*, State Department of Education, Montgomery, Alabama, August 8, 1972. Note that the number reportedly identified is often higher than other estimates of the total handicapped youth in the population.

^gU.S. Department of Health, Education and Welfare, *National Health Survey, Prevalence of Selected Impairments, July 1963-June 1965*, Public Health Service, p. 9.

^hKenneth Trouern-Trend, *Blindness in the United States*, Travelers Research Center, Hartford, Conn., 1968.

ⁱRossmiller, op. cit., p. 121. This is the estimate used in the Rossmiller study after a review of other prevalence data.

^jEstimated Statistics on Blindness and Vision Problems, National Society for the Prevention of Blindness, Inc., New York, New York, 1966.

^kDerived from estimates in *Human Communications and Its Disorders--An Overview*. A report of the National Advisory Neurological Diseases and Stroke Council of the National Institute of Neurological Diseases and Stroke, National Institutes of Health, U.S. Department of Health, Education and Welfare, Bethesda, Maryland, 1969.

^lIncluded with crippled.

more detailed discussions of definitions and incidence rates than we present here, refer to the Trouern-Trend study cited earlier and to a report by the National Society for the Prevention of Blindness, Inc.,² and one by the Organization for Social and Technical Innovation, Inc.³

The usual definition of legal blindness is that a person's visual acuity for distant vision does not exceed 20/200 in the better eye, with best correction; or his visual acuity is more than 20/200 but the widest diameter of his field of vision subtends an angle no greater than 20°. Within this category of legal blindness the quality of vision varies widely.

After considering many data sources, the National Society for the Prevention of Blindness⁴ indicates that the best data available suggest about 1 child in 4 of school age in the United States needs eye care; about 1 in 500 is partially sighted (i.e., uses sight as a chief channel of learning, including 42 percent of legally blind children and those with acuity after correction of better than 20/200 but less than 20/70⁵); and about 1 in 2000 (0.054 in 100) is legally blind.

Other estimates were shown in Table A2. The data indicate that the education agencies in the states are reporting a higher incidence of visual impairments than the National Health Survey and the Model Reporting Areas for Blindness Statistics. This is primarily due to differences in definition. One need not be legally blind to be visually handicapped in terms of the education process. North Dakota, for example, classified children with only 20/70 vision in the better eye after corrections as partially sighted. As we indicated earlier, the handicap definition should depend on how vision relates to the service, e.g., the education process. It is easy to see that the sole use of the classification of legal blindness is misleading in terms of prescriptive action that the schools or other service agencies must take.

Table A3 presents estimates of the percentage of the legally blind with various degrees of vision. Only a relatively small fraction (16 percent) are totally blind.

Some previous estimates of the prevalence of blindness have assumed that it is not distributed randomly but is in fact related to such things as income and race.⁶ If this is true, the use of average U.S. rates for individual states could be misleading.

Using the NSPB prevalence estimates, and the fact that there were 83.8 million youth aged 0-21 in the United States in 1970, implies that in 1970 there were about 21 million youth who required eye care; 45,000 legally blind youth; and 168,000 partially sighted youth, of whom perhaps 20,000 were legally blind. If one defines partially sighted to include measurable acuity less than 20/70, with correction, then there are perhaps 180,000 partially sighted youth, of whom 32,000 are legally blind.

HEARING IMPAIRMENT

Hearing losses may be grouped into two broad categories: deafness, or sense of

² *Estimated Statistics on Blindness and Vision Problems*, National Society for the Prevention of Blindness, New York, New York, 1966.

³ *Blindness and Services to the Blind in the U.S.*, OSTI Press, Cambridge, Mass., 1971.

⁴ *Estimated Statistics on Blindness and Vision Problems*.

⁵ The approximate acuity with correction at which it becomes possible for the person to read ordinary newsprint.

⁶ Kenneth Trouern-Trend, *Blindness in the United States*, Travelers Research Center, Hartford, Conn., 1968, p. 5.

Table A3
DEGREE OF VISION: AGES 5-19

	Percent
Absolute blindness	16
Light perception	14
Light projection	1
Less than 5/200	8
5/200 but less than 10/200	6
10/200 but less than 20/200	12
20/200	26
Field restriction	1
Unknown	16

SOURCE: Kenneth Trouern-Trend, *Blindness in the United States*, 1968. These figures represent the degree of vision of those registered in the Model Reporting Areas in 1965.

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. For a more detailed discussion of definitions and sources of prevalence data than we present here, refer to the NINDS report.⁷ According to that report, "Deafness has never been defined to the satisfaction of all authorities," and "... the task of ascertaining how many deaf persons there are in this country has never been accurately performed." We would add that the quality of the statistics on the hard of hearing is considerably worse than that for the deaf. The NINDS report suggests that the most widely accepted definition of deafness is as follows:

Those in whom the sense of hearing is nonfunctional for the ordinary purposes of life. This general group is made up of two distinct classes based entirely on the time of the loss of hearing. a) The congenitally deaf: those who are born deaf. b) The adventitiously deaf: those who were born with normal hearing but in whom the sense of hearing becomes nonfunctional later through illness or accident.⁸

A more detailed and specific classification was used in the 1960-1962 U.S. Public Health Service Health Examination Survey. The breakdown of hearing loss is based on the decibels (dB) of sound loss in the 500 to 2000 Hertz range, which covers most of the speech range. The average hearing level in the better ear is divided into four ranges with the associated functional interpretation:

- 41-55 dB: Frequent difficulty with normal speech
- 56-70 dB: Frequent difficulty with loud speech

⁷ National Advisory Neurological Diseases and Stroke Council of the National Institute of Neurological Diseases and Stroke, *Human Communication and Its Disorders—An Overview*, National Institutes of Health, U.S. Department of Health, Education and Welfare, Bethesda, Maryland, 1969.

⁸ The distinction is made because in the former case language development could not occur with the aid of the sense of hearing.

- 71-90 dB: Understands only shouted or amplified speech
- 91+ dB: Usually cannot understand even amplified speech

Other breakdowns use more categories, slightly different dB breakpoints, or slightly different functional interpretations, but are generically the same. For example, Rossmiller uses a classification wherein a hearing loss of 20-45 decibels in at least two frequencies in the speech range is classified as mildly hard of hearing.⁹ Deaf or severely hard of hearing are those with a hearing loss of between 75 to 80 decibels or greater across the speech range without the use of hearing aids.¹⁰ The National Health Interview Survey takes a less scientific approach when it asks respondents if they feel they have deafness or serious trouble hearing with one or both ears. A different type of hearing disorder, on which very little data are available, is one in which the level of sound heard may or may not be normal, but there are dysacusic disturbances primarily symptomized by garbled hearing.

The NINDS report estimates there were 236,000 deaf persons of all ages in the United States in 1970. Using their same data source,¹¹ we note a prevalence of deafness in persons under age 15 of about 53 per 100,000 and 76 per 100,000 aged 15-24. Using these rates, we estimate the 1970 aged 0-21 deaf population is approximately 50,000. The NINDS report estimates that "about 8,500,000 Americans (in 1970) have auditory problems of one type or another which are less severe than deafness but which impair communication . . . about 4.5 percent (circa 360,000) are under 17 years."¹² If we extrapolate at the same rate to the 0-21 age range, the estimate is 440,000, or 0.525 percent of those in that age range.

Prevalence estimates from various sources are shown in Table A4.

Table A4

PREVALENCE OF HEARING IMPAIRMENTS, BY DEGREE OF IMPAIRMENT
(Percent of total youth population)

Degree of Impairment	Estimate								
	(a)	(b)	(c)	(d)	(e)	(f)	(g)	(i)	(k)
Hard of hearing	0.500	0.500	{ 0.08 ¹	2.0	0.85	0.200	{ 0.95 ¹	{ 0.1 ¹	0.525
Deaf	0.075	0.075		0.1	0.15	0.003			0.060

SOURCE: See Table A2 for sources a through k.

¹ Combined.

SPEECH IMPAIRMENT

Speech impairment includes absence of a larynx, stammering, stuttering, poor

⁹ R. A. Rossmiller, J. A. Hale, and L. E. Frohreich, *Educational Programs for Exceptional Children: Resource Configurations and Costs*, National Educational Finance Project, Special Study No. 2, Department of Educational Administration University of Wisconsin, Madison, Wisconsin, August 1970, p. 72.

¹⁰ Ibid, p. 73.

¹¹ "Statistical Information Concerning the Deaf and Hard of Hearing in the U.S.," *American Annals of the Deaf*, Vol. 104, 1959, pp. 265-270.

¹² *Human Communication and Its Disorders—An Overview*, p. 13.

articulation, and other ill-defined troubles with speech. Since there is no precise definition of speech impairment, it would seem reasonable that there might be no reasonable consensus about the prevalence of this impairment. This tends to be confirmed by the data in Table A2. For a discussion of various prevalence data, see the NINDS report.¹³ In 1970 there were about 63 million youth aged 5-21, which leads to an estimated 2,200,000 speech impaired youth if a 3.5-percent rate is used, or to an estimated 3,140,000 if a 5-percent rate is used.

The National Health Survey (NHS) gives by far the lowest estimate. It was based upon the response to the question about whether there were any speech defects in the family. One cause could be that most people do not think that their speech difficulties are as significant as a speech therapist would. Another cause is that cases of cleft palate and deaf mutism were classified in other categories rather than speech impaired in the NHS, though they might benefit from speech therapy.

CRIPPLED AND OTHER HEALTH IMPAIRED

Crippled and other health impaired includes physical handicaps not characterized as speech, hearing, or visual handicaps. Crippled includes orthopedic or muscular impairments such as the absence, paralysis, or other impairment of the limbs, back, or trunk. This category also includes children with chronic disease or other relatively long-term physical impairment such as problems involving the heart, blood, respiratory, or digestive systems.

The estimates of the prevalence of a crippling or health condition will be different from estimates of a "handicapping" crippling or health condition. That is, a loss of a finger may not interfere with the educational process, and hence the child would not be considered handicapped with respect to that service. From an aesthetic or medical viewpoint, however, the child could be considered crippled. The estimates for the prevalence rates shown in Table A2 are mainly from education sources and hence may underestimate those actually crippled or other health impaired. This is suggested in the table, where the National Health Survey found 2.6 percent of the population physically handicapped, which is well above any of the estimates from the other sources.

Using the Mackie, Williams, and Hunter¹⁴ rate, which is consistent with the rates observed in various service programs, would result in an estimated 1,676,000 youth aged 0-21 with these types of handicaps.

MENTAL RETARDATION

Definitions and prevalence data are presented and discussed in Sec. 10 of this report, which describes mental health agency programs. Ronald Conley performed a more extensive review of rates of mental retardation than presented here; the

¹³ Ibid., pp. 16-19.

¹⁴ *Statistics of Special Education for Exceptional Children and Youth, 1957-1958*, USOE Bulletin No. OE-35048-58, 1963.

reviewed studies reported rates between 1.2 and 18.4 percent.¹⁵ Conley uses a rate of nearly 4 percent in his work on the costs and benefits of mental retardation programs. While this is close in absolute terms to the 2.3 percent used by BEH, the relative difference in percentage terms is 74 percent. Extrapolating Conley's estimates to the entire 0-21 age range yields a population estimate of about 2.8 million.

EMOTIONALLY DISTURBED

When psychiatrists agree upon what mental health is, and reliable instruments are developed to measure it, then it will be possible to obtain a consensus on the prevalence of emotional disturbance in youth. Current definitions leave a great deal to judgment about whether a child is emotionally disturbed or not. For example, emotionally disturbed children have been defined as those demonstrating one or more of the following characteristics:¹⁶

1. An inability to learn which cannot be explained by intellectual, sensory or health factors.
2. An inability to build or maintain satisfactory interpersonal relationships with peers and teachers.
3. Inappropriate types of behavior or feelings under normal conditions.
4. A general, pervasive mood of unhappiness or depression.
5. A tendency to develop physical symptoms, pains or fears associated with personal or school problems.

Just what is considered "inappropriate" behavior under "normal" conditions will vary by individual assessor. Since teachers are a principal source identifying handicap and are usually not trained to identify the emotionally disturbed population, a large margin for error is introduced. A tendency may prevail to classify those who are difficult to handle in the classroom as emotionally disturbed. One would expect a relatively large variance in the estimates of the prevalence of emotionally disturbed youth. Table A2 tends to bear this out. If one applies the BEH rate to the aged 3-21 population, one estimate would be about 1.5 million youth.

LEARNING DISABLED

Learning disabled children have been defined as follows:

Children are said to have special learning disabilities when they have a disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, which may manifest itself in imperfect function in listening, speaking, writing, reading, spelling,

¹⁵ R. B. Conley, "An Assessment of the Economic and Non-Economic Costs and Benefits of Mental Retardation Programs," in J. S. Cohen et al., *Benefit Cost Analysis for Mental Retardation Programs: Theoretical Considerations and a Model for Application*, Institute for the Study of Mental Retardation and Related Disabilities, University of Michigan, Ann Arbor, Michigan, 1971.

¹⁶ Rossmiller, Hale, and Frohreich, p. 95.

or doing mathematical calculations. Such disorders include conditions described as perceptual handicaps, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia but do not include those with learning problems primarily the result of visual, hearing, or motor handicaps or mental retardation.¹⁷

This definition is not very precise. Many responsible for identifying learning disorders have not been trained for such work, and, as a result, many of the classifications are basically educated guesses unsupported by research evidence.¹⁸

Estimates of the prevalence of the learning disabled cover a wide range. The Fleischmann Report quoted one figure as high as 20 percent.¹⁹ Again, however, we have a problem of determining where the cutoff should be made in the continuum of learning disorders. Unless that cutoff is standardized (or various levels of severity are standardized) at an educationally meaningful point, the estimates of prevalence cannot be very helpful as a basis for policy development.

Table A2 contains various estimates of the prevalence of a learning handicap. The Wisconsin study found this disorder to be rare. Only 26 out of 100,000 children would be affected with this type of learning disorder if the Wisconsin estimate were correct. More dramatically, only one out of eight elementary schools with an enrollment of 600 each would be expected to have a learning disabled child. If the Nebraska estimate were correct, then each of these same schools would have 42 learning disabled children. The discrepancy is obvious, but at this point, without more precision of definition and data, it is irreconcilable. Applying BEH prevalence rates to the age 3-21 population leads to an estimate of 740,000 learning disabled in that age range in 1970.

¹⁷ *Minimal Brain Dysfunction in Children*, Public Health Service Publication No. 20015, 1969, p. 2.

¹⁸ E. C. Frierson and Walter Barbe, *Educating Children With Learning Disabilities: Selected Readings*, Appleton-Century-Croft, New York, 1967, p. 3.

¹⁹ M. Fleischmann, *Report of the New York State Commission on the Quality, Cost and Financing of Elementary and Secondary Education, Vol. II*, Albany, New York, 1972.

Appendix B

SURVEY OF STATE AGENCIES SERVING HANDICAPPED YOUTH

This survey conducted by The Rand Corporation for HEW in late 1972 had two purposes: (1) to acquire information on the actual dimensions of states' programs for handicapped youth, including budgetary data, types of services rendered, and the numbers and types of persons receiving assistance; and (2) to obtain the views of high-level state agency officials on problems and possible ways of improving assistance to physically and mentally handicapped youth.

Program descriptive information was received from 179 of the approximately 300 state agencies surveyed, for an overall response rate of 60 percent. Fewer than half of the responses, however, included views on problems or potential solutions.

The questionnaires were sent to six basic types of agencies in each state: Crippled Children's Service, Mental Health, Public Health, Public Welfare, Special Education, and Vocational Rehabilitation. The mailing lists in Appendix C were obtained from each of the relevant Federal agencies. Where more or fewer agencies in a given state were responsible for assistance to handicapped youth, the mailing list was correspondingly modified.

The questionnaires are included in Appendix D. They were developed and modified based on interviews with HEW agencies funding programs that in whole or in part reach handicapped youth. They were also modified based on interviews with officials in relevant agencies in the states of Arkansas, California, Illinois, Massachusetts, and Wyoming. Draft questionnaires were pretested in the latter three states before submission to the U.S. Office of Management and Budget (OMB) for clearance. After the questionnaires received OMB approval, they were further tested in mailings to a few randomly selected states.

Every effort was made to ensure a high response rate to the questionnaire. In the full mail survey, initial nonrespondents were sent a second reminder set of questionnaires at the end of six weeks after initial survey.

Approximately one-third of the agencies that did not respond wrote or called to explain why they were unable to cooperate. Some lessons can be learned from the reasons given for not responding. The reasons cited for not completing the questionnaires, along with the number of state agencies citing each reason, are given in Table B1. Basically, the agencies either did not have the basic management data we

Table B1

REASONS GIVEN FOR NONRESPONSE TO THE MAIL SURVEY

Reason	Number of Times Reason was Cited
Data are not available	12
Data are not available for handicapped youth separately from other persons	10
Data exist only in individual client files, and are "impossible" to retrieve	5
State funds are used but the counties run the program and have the data	2
Insufficient staff available to take time from per- formance of prime service responsibilities	8
Insufficient agency staff available, but will open files to Rand staff members	4
Too busy with state agency business now, but could respond in a couple of months	4
Survey did not have prior clearance from the National Council of State Administrators of Vocational Re- habilitation Agencies	6
Too many surveys are conducted; all are rejected	5

requested, or had insufficient staff to collect the data for completion of the questionnaire. It appears that state agencies are grossly overburdened by numerous questionnaires. One official who kept track over a long period reported an average of five per week. Thus, the self-preservation tendency is to reject most or all surveys. One state official wrote, "I would suggest you develop a system or technique of information gathering that in no way involves the time of any agency administrator and/or professional or clerical staff." The National Council of State Administrators of Vocational Rehabilitation (CSAVR) is developing a new policy, not fully operational at the time of Rand's survey, of not having state agencies respond to any survey unless it has prior clearance from the Council.

Several officials in those states that did complete our questionnaire were surprised and enlightened by the data they collected for us and, as a result, thanked us for conducting the survey. Overall, the responses were excellent in the sense that state agencies generally were very cooperative and appeared to be sending all relevant available information. The responses were disappointing in the sense that information available in many state agencies is not broken down in such a way that services for handicapped youth can be analyzed separately from services for non-handicapped youth or for adults. Public health and public welfare programs are two areas in which data typically are not tabulated separately for handicapped youth, although the agencies provide significant amounts of service to that group. Many state agencies summarize data on individual clients only when state budgetary processes or Federal reporting regulations require it.

Appendix C

STATE AGENCIES SURVEYED ON PROGRAMS FOR HANDICAPPED YOUTH

This appendix contains a listing, by state, of the major agencies providing services and assistance to physically or mentally handicapped youth. Six basic types of agencies are included: Crippled Children's Service, Mental Health, Public Health, Public Welfare, Special Education, and Vocational Rehabilitation. Because of variations in the organization of state governments, more or fewer than six agencies may be cited for a particular state. This listing was compiled at the request of the Office of the Secretary of Health, Education and Welfare and was used in conducting a survey to provide information for this research project. The listing was compiled from a variety of sources* and updated where feasible by the relevant Federal agency.

* Unpublished list of state agencies receiving funds from the Social and Rehabilitation Service, including the Assistance Payments Administration and the Rehabilitation Services Administration, of the U.S. Department of Health, Education and Welfare (D/HEW), August 10, 1972.

Directory of Special Education Personnel in State Education Agencies, D/HEW, November 1971, updated to August 1972.

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Maternal and Child Health Service Programs, D/HEW, Public Health Service, 1972.

1971 Public Welfare Directory, Vol. XXXII, July 1971.

Directory of Agencies Serving the Visually Handicapped in the United States, 16th ed., American Foundation for the Blind, 1969.

American Annals for the Deaf, Directory of Programs and Services, Vol. 117, No. 2, April 1972.

ALABAMA

Mr. Sam L. Canerday
Crippled Children's Service
Dept of Education
2129 E. South Blvd
Montgomery, Alabama

Mr. George M. Hudson
Director, Division of Rehabili-
tation and Crippled Children
State Dept of Education
Montgomery, Alabama 36104

Mr. Reuben K. King
Commissioner, State Dept of
Pensions and Security
64 North Union Street
Montgomery, Alabama 36104

Ira L. Myers, M.D.
State Health Officer,
State Dept of Public Health
State Office Building
Montgomery, Alabama 36104

Mr. Clinton R. Owens
Chief Consultant and Supervisor,
Exceptional Children and Youth
State Dept of Education
Montgomery, Alabama 36104

Mr. John P. Parsons
Supervisor, Services to the
Blind and Deaf Division
State Dept of Education
Montgomery, Alabama

Stonewall B. Stickney, M.D.
Commissioner of Mental Health,
Dept of Mental Health
502 Washington Avenue
Montgomery, Alabama 36104

ALASKA

Donald K. Freedman, M.D.
Director, Division of Public
Welfare
Dept of Health and Social Services
Pouch H
Juneau, Alaska 99801

Mr. Stanley P. Harris
Director, Division of Public
Welfare
Dept of Health and Social Services
Pouch H
Juneau, Alaska 99801

Mr. Jeff C. Jeffers
Acting Director, Division of
Instructional Services
State Dept of Education
Pouch F
Juneau, Alaska 99801

Carl D. Koutsky, M.D.
Acting Director, Dept of Health
and Social Services
Pouch H
Juneau, Alaska 99801

Thomas McCabe, M.D.
Chief, Child Health
State Dept of Health and Welfare
Pouch H
Juneau, Alaska 99801

ARIZONA

Mr. Robert A. Batten, Jr.
 Director, Division of Vocational
 Education
 55 East Thomas Road, Suite 101
 Phoenix, Arizona 85012

Warren A. Colton, Jr., M.D.
 Medical Director, State of Arizona
 Crippled Children's Services
 1825 E. Garfield Street
 Phoenix, Arizona 85006

Mr. John O. Graham
 Commissioner, State Dept of
 Public Welfare
 1624 West Adams Street
 Phoenix, Arizona 85007

Mr. Donald M. Johnson
 Director, Division of Special
 Education
 Dept of Education
 1730 West Adams
 Phoenix, Arizona 85007

Louis C. Kossuth, M.D.
 Commissioner, State Dept
 of Health
 1624 W. Adams Street
 Phoenix, Arizona 85007

Mr. Robert E. Lofgren
 Director, Division of Mental
 Health Services
 Dept of Health
 1624 W. Adams Street
 Phoenix, Arizona 85007

ARKANSAS

Mr. Thomas V. Hicks
 Coordinator, Special Education
 Arch Ford Education Bldg.
 Little Rock, Arkansas 72201

George W. Jackson, M.D.
 Commissioner, Mental Health
 Services
 4313 W. Markham Street
 Little Rock, Arkansas 72201

Mr. Dalton Jennings
 Division of Social Services
 Capitol Mall
 Little Rock, Arkansas

Mr. Charles McGibbons
 Crippled Children's Service
 13th and Wolfe
 Little Rock, Arkansas

Dr. Donald G. Thurman
 Rehabilitation Services
 P.O. Box 3781
 Little Rock, Arkansas 72203

Dr. John Harrel
 State Dept of Health
 4815 W. Markham Street
 Little Rock, Arkansas 72201

CALIFORNIA

Mr. Leslie Brinegar, Associate
 Superintendent
 Chief, Division of Special
 Education
 State Dept of Education
 Sacramento, California 95814

Mr. Lockwood Carr
 Chief, Program Analysis Bureau
 Dept of Health Care Services
 714 P Street
 Sacramento, California 95814

CALIFORNIA (Cont.)

Mr. Charles P. Devereaux
 Dept of Social Welfare
 744 P. Street
 Sacramento, California 95814

Dr. Charles R. Gardipee
 Bureau of Mental Retardation
 Services
 1625 Shattuck Avenue
 Berkeley, California 94709

Dr. Esmond Smith
 Bureau of Crippled Children's
 Services
 1625 Shattuck Avenue
 Berkeley, California

J. M. Stubblebine, M.D.
 Director, State Dept of Mental
 Hygiene
 744 P Street
 Sacramento, California 95814

Mr. James A. Walker
 Human Relations Agency
 714 P Street
 Sacramento, California 95814

COLORADO

Ms. Charline J. Birkins
 Director, Division of Public
 Welfare
 State Dept of Social Services
 1575 Sherman Street
 Denver, Colorado 80203

R. L. Cleere, M.D., M.P.H.
 Executive Director,
 Colorado Dept of Health
 4210 East 11th Avenue
 Denver, Colorado 80220

Mr. Daniel J. Gossert
 Handicapped Children's Program
 Colorado Dept of Health
 4210 E. Eleventh Avenue
 Denver, Colorado 80220

Parnell McLaughlin, Ed.D.
 Director, Division of Rehabilitation
 State Dept of Social Services
 1575 Sherman Street
 Denver, Colorado 80203

Mr. Marvin L. Meyers
 Chief, Division of Mental
 Retardation
 Dept of Institutions
 328 State Services Building
 Denver, Colorado 80203

Mr. Dave Miles
 Director, Pupil Personnel Unit
 State Dept of Education
 State Office Building
 Denver, Colorado 80203

Mr. Hilbert Schauer
 Director, Dept of Institutions
 328 State Services Building
 Denver, Colorado 80203

Mr. Con F. Shea
 Executive Director, State Dept
 of Social Services
 1575 Sherman Street
 Denver, Colorado 80202

CONNECTICUT

Mr. Robert W. Bain
 Division of Vocational
 Rehabilitation
 600 Asylum Avenue
 Hartford, Connecticut 06105

Franklin M. Foote, M.D.
 Commissioner of Health,
 State Dept of Health
 79 Elm Street
 Hartford, Connecticut 06115

George L. Hamilton, Jr., M.D.
 Chief, Crippled Children's
 Section
 State Dept of Health
 79 Elm Street
 Hartford, Connecticut 06106

Mr. Francis A. McElaney
 Bureau Chief, Bureau of Pupil
 Personnel and Special
 Educational Services
 State Dept of Education
 Hartford, Connecticut 06115

Mr. Ernest A. Shepherd
 Commissioner, State Dept of
 Mental Health
 90 Washington Street
 Hartford, Connecticut 06115

Mr. Henry C. White
 Commissioner, State Welfare
 Dept
 1000 Asylum Avenue
 Hartford, Connecticut 06105

DELAWARE

James E. Carson, M.D.
 Division of Mental Health and
 Mental Retardation
 Administration Building
 Delaware State Hospital
 New Castle, Delaware 19720

Mr. Robert C. Hawkins
 Director, Instruction Division
 State Dept of Public Instruction
 Townsend Building
 Dover, Delaware 19901

Mr. John E. Hiland
 Chief, Division of Social Services
 State Dept of Health and Social
 Services
 305 West 8th Street
 Wilmington, Delaware 19801

Floyd I. Hudson, M.D.
 Director, Division of Physical
 Health
 Federal and D Streets
 Dover, Delaware 19901

Albert L. Ingram, Jr., M.D.
 Secretary, State Dept of Health
 and Social Services
 3000 Newport Gap Pike
 Wilmington, Delaware 19808

Mr. Donald H. Kappes
 Vocational Rehabilitation
 Services
 1500 Shallcross Avenue
 P.O. Box 1190
 Wilmington, Delaware 19899

FLORIDA

Mr. E. Douglas Ensley
 Director, Division of Family Services
 State Dept of Health and
 Rehabilitation
 P.O. Box 2050
 5920 Arlington Expressway
 Jacksonville, Florida 32203

Mr. Jack McAllister
 Director, Division of Retarda-
 tion
 Larson Building, Room 460
 Tallahassee, Florida 32304

FLORIDA (Cont.)

Mr. Craig Mills
 Director, Division of Vocational
 Rehabilitation
 Dept of Health and Rehabilita-
 tion Services
 725 S. Bronough Street, Room 254
 Tallahassee, Florida 32304

W. D. Rogers, M.D.
 Director, Division of Mental
 Health
 Chattahoochee, Florida 32324

Mr. F. Edwards Rushton
 Director, Bureau of Crippled
 Children
 107 W. Gaines Street
 Tallahassee, Florida 32304

Wilson T. Sowder, M.D.
 Director, Division of Health
 and Rehabilitative Services
 P.O. Box 210
 Jacksonville, Florida 32201

Mr. Landis M. Stetler
 Administrator, Exceptional
 Child Education
 Florida Dept of Education
 Tallahassee, Florida 32304

GEORGIA

Dixon A. Lackey, Jr., M.D.
 Acting Director, State Dept
 of Public Health
 47 Trinity Avenue, S.W.
 Atlanta, Georgia 30334

Mr. Herbert D. Nash
 Director, Special Education
 Program
 Division of Elementary and
 Secondary Education
 State Dept of Education
 Atlanta, Georgia 30334

Mr. Thomas M. Parham
 Director, Dept of Family and
 Children Services
 State Office Building
 Atlanta, Georgia 30334

Mr. John S. Prickett, Jr.
 Director, Division of Voca-
 tional Rehabilitation
 629 State Office Building
 Atlanta, Georgia 30334

John H. Veneble, M.D.
 Director of Public Health
 47 Trinity Avenue, S.W.
 Atlanta, Georgia 30334

HAWAII

Honorable Shiro Amioka
 Superintendent of Education
 P.O. Box 2360
 Honolulu, Hawaii 96804

Angie Connor, M.D.
 Crippled Children's Services
 Branch
 Dept of Health
 P.O. Box 3378
 Honolulu, Hawaii 96801

HAWAII (Cont.)

Wilbur S. Lummis, Jr., M.D.
Hawaii Dept of Health
P.O. Box 3378
Honolulu, Hawaii 96801

Mr. Kuniiji Sagara
Administrator, Vocational Rehabil-
itation and Services for the Blind
Dept of Social Services
P.O. Box 339
Honolulu, Hawaii 96809

Mr. Myron B. Thompson
Director, State Dept of Social
Services
P.O. Box 339
Honolulu, Hawaii 96809

J. Kendall Wallis, M.D.
Chief, Mental Health Division
Dept of Health
P.O. Box 3378
Honolulu, Hawaii 96801

IDAHO

Terrell O. Carver, M.D.
Administrator of Health,
Idaho State Dept of Health
Statehouse
Boise, Idaho 83707

Mr. B. Child
Commissioner, State Dept of
Public Assistance
P.O. Box 1189
Boise, Idaho 83701

Mr. John F. Comba
Director of Special Education,
Instructional Services
State Office Building
Boise, Idaho 83707

John R. Marks, M.D.
Director, Mental Retardation and
Child Development Division
Idaho State Dept of Health
Statehouse
Boise, Idaho 83707

Myrick W. Pullen, Jr., M.D.
Director, Division of Mental
Health
Idaho State Dept of Health
Statehouse
Boise, Idaho 83707

Jacob E. Wyatt, M.D.
Director, Maternal and Child
Health
Idaho State Dept of Health
Statehouse
Boise, Idaho 83707

ILLINOIS

Albert J. Glass, M.D.
Director, State Dept of Mental
Health
160 N. La Salle Street
Chicago, Illinois 60601

Edward F. Lis, M.D.
Director, Division of Services
for Crippled Children
540 Iles Park Place
Springfield, Illinois 62703

Mr. Fred Rozum
Assistant Superintendent, Dept
for Exceptional Children
1020 S. Spring Street
Springfield, Illinois 62706

Mr. Alfred Slicer
Director, Division of Vocational
Rehabilitation
State Board of Vocational Edu-
cation and Rehabilitation
623 E. Adams Street
Springfield, Illinois 62706

ILLINOIS (Cont.)

Mr. Harold O. Swank
 Director, Illinois Dept of
 Public Aid
 618 E. Washington Street
 Springfield, Illinois 62706

Franklin D. Yoder, M.D.
 Director of Public Health,
 Illinois Dept of Public Health
 535 W. Jefferson Street
 Springfield, Illinois 62706

INDIANA

Mr. Gilbert A. Bliton
 Director, Division of Special
 Education
 Dept of Public Instruction
 108 State Office Building
 Indianapolis, Indiana 46204

Andrew C. Offutt, M.D.
 Commissioner, State Board of
 Health
 1330 W. Michigan Street
 Indianapolis, Indiana 46206

Mr. Raymond F. Handley
 Director, Indiana Agency for the
 Blind
 State Board of Health
 536 W. 30th Street
 Indianapolis, Indiana 46223

Mr. William R. Sterrett
 Administrator, Indiana Dept
 of Public Welfare
 100 N. Senate Avenue, Room 701
 Indianapolis, Indiana 46204

William E. Murray, M.D.
 Commissioner, State Dept of Mental
 Health
 1315 W. Tenth Street
 Indianapolis, Indiana 46202

Mr. Richard H. Wenzel
 Division of Services for
 Crippled Children
 State Dept of Public Welfare
 100 N. Senate Avenue
 Indianapolis, Indiana 46220

IOWA

Mr. James N. Bethel
 Bureau of Mental Retardation
 Services
 Iowa Dept of Social Services
 Lucas State Office Bldg.
 Des Moines, Iowa 50319

Mr. Kenneth Jernigan
 Director, State Commission for
 the Blind
 4th and Keosauqua
 Des Moines, Iowa 50309

Mr. Richard E. Fischer
 State Director, Division of
 Special Education
 State Dept of Public Instruction
 Grimes State Office Bldg.
 Des Moines, Iowa 50319

John C. MacQueen, M.D.
 Executive Officer and Medical
 Director,
 State Services for Crippled
 Children
 University of Iowa
 Iowa City, Iowa 52241

Mr. James N. Gillman
 Commissioner, Iowa Dept of
 Social Services
 Lucas State Office Bldg.
 Des Moines, Iowa 50319

Herbert L. Nelson, M.D.
 Director, Iowa Mental Health
 Authority
 Psychopathic Hospital
 500 Newton Road
 Iowa City, Iowa 52241

IOWA (Cont.)

Arnold M. Reeve, M.D.
 Commissioner, State Dept of Health
 Lucas State Office Bldg.
 Des Moines, Iowa 50319

Mr. Jerry L. Starkweather
 Associate Superintendent
 and Director,
 Division of Rehabilitation
 Education and Services
 State Board of Public
 Instruction
 801 Bankers Trust Bldg.
 Des Moines, Iowa 50309

Director, Bureau of Mental
 Health Services
 Iowa Dept of Social Services
 Lucas State Office Bldg.
 Des Moines, Iowa 50319

KANSAS

Robert A. Haines, M.D.
 Director of Institutions,
 State Dept of Social Welfare
 State Office Building
 Topeka, Kansas 66612

Dr. Robert C. Harder
 Director, State Dept of Social
 Welfare
 State Office Building
 Topeka, Kansas 66612

Mr. Harry E. Hayes
 Director, Division of Services
 for the Blind and Visually
 Handicapped
 State Dept of Social Welfare
 State Office Building
 Topeka, Kansas 66612

Roy C. Knappenberger, M.D.
 Medical Director, Kansas
 Crippled Children Commission
 727 First National Bank Building
 Wichita, Kansas 67202

Mr. Marvin Larson
 Director, Division of Voca-
 tional Rehabilitation
 Dept of Social Welfare
 State Office Building,
 Room 1145-E
 Topeka, Kansas 66612

Edwin D. Lyman, M.D.
 Executive Secretary and State
 Director of Health,
 State Dept of Health
 State Office Building
 Topeka, Kansas 66612

Mr. James E. Marshall
 Director, Division of Special
 Education
 State Dept of Education
 120 E. Tenth Street
 Topeka, Kansas 66612

KENTUCKY

Mr. Ben F. Coffman
 Bureau of Rehabilitation Services
 State Office Building
 High Street
 Frankfort, Kentucky 40601

Mr. Merritt S. Deitz, Jr.
 Commissioner, State Dept of
 Economic Security
 Capital Annex Office Building
 Frankfort, Kentucky 40601

KENTUCKY (Cont.)

Ms. Stella A. Edwards
 Director, Division of Special
 Education
 State Office Building
 Frankfort, Kentucky 40601

Dale Farabee, M.D.
 Commissioner, Kentucky Dept of
 Mental Health
 P.O. Box 678
 Frankfort, Kentucky 40601

Ms. Tavner Johnston
 Executive Director, Bureau
 of Public Assistance
 State Dept of Economic Security
 Capitol Annex Office Building
 Frankfort, Kentucky 40601

Margaret A. Limper, M.D.
 Medical Director, Commission
 for Handicapped Children
 1405 E. Burnett Avenue
 Louisville, Kentucky 40217

W. P. McElwain, M.D.
 Commissioner of Health,
 State Dept of Health
 275 East Main Street
 Frankfort, Kentucky 40601

LOUISIANA

William P. Addison, M.D.
 Commissioner of Mental Health,
 State Dept of Hospitals
 655 North Fifth Street
 Baton Rouge, Louisiana 70804

Mr. Garland L. Bonin
 Commissioner, Louisiana Dept of
 Public Welfare
 P.O. Box 44065
 Baton Rouge, Louisiana 70804

Mr. Vernon Broussard
 Director, Division for the Blind
 State Dept of Public Welfare
 P.O. Box 44065
 Baton Rouge, Louisiana 70804

Mr. Otto P. Estes
 Commissioner of Mental Retardation,
 State Dept of Hospitals
 655 North Fifth Street
 Baton Rouge, Louisiana 70804

Ben Freedman, M.D.
 Chief, Section of Crippled
 Children's Services
 State Board of Health
 P.O. Box 60630
 New Orleans, Louisiana 70160

Mr. Joseph Glorioso
 Director of Special Education,
 State Dept of Education
 P.O. Box 44064
 Baton Rouge, Louisiana 70804

Andrew Hedmeg, M.D.
 State Dept of Health
 P.O. Box 60630
 New Orleans, Louisiana 70160

MAINE

Dr. Albert Anderson
 Director, Bureau of Mental
 Retardation
 Dept of Mental Health and
 Corrections
 State House
 Augusta, Maine 04330

Dean H. Fisher, M.D.
 Commissioner, Maine Dept of
 Health and Welfare
 State House
 Augusta, Maine 04330

Peter J. Leadley, M.D.
 Director, Bureau of Health
 State Dept of Health and
 Welfare
 State House
 Augusta, Maine 04330

William E. Schumcher, M.D.
 Director, Bureau of Mental Health
 State Dept of Mental Health and
 Corrections
 State Office Building
 Augusta, Maine 04330

Ms. Beverly V. Trenholm
 Director, Bureau of Guidance,
 Special, and Adult Education
 State Dept of Education
 Augusta, Maine 04330

Mr. Robert O. Wyllie
 Director, Bureau of Social
 Welfare
 State Dept of Health and Welfare
 State House
 Augusta, Maine 04330

MARYLAND

Mr. J. Leo Delaney
 Assistant State Superintendent
 in Vocational Rehabilitation,
 State Board of Vocational
 Education
 2100 Guilford Avenue
 Baltimore, Maryland 21218

Judson Force, M.D.
 Chief, Division of Crippled
 Children's Services
 State Office Building
 301 W. Preston Street
 Baltimore, Maryland 21201

Mr. Raleigh C. Hobson
 Director, Social Services Admin-
 istration
 1315 St. Paul Street
 Baltimore, Maryland 21202

Mr. Stanley Mopsik
 State Dept of Education
 600 Wyndhurst Avenue
 Baltimore, Maryland 21210

Jean R. Stifler, M.D.
 Dept of Health and Mental
 Hygiene
 State Office Building
 301 West Preston Street
 Baltimore, Maryland 21201

MASSACHUSETTS

Milton Greenblatt, M.D.
 Commissioner of Mental Health,
 State Dept of Mental Health
 190 Portland Street
 Boston, Massachusetts 02114

Mr. William Keating
 Special Education Division,
 State Dept of Education
 182 Tremont Street
 Boston, Massachusetts 02111

Mr. John S. Levis
 Commissioner of Rehabilitation,
 Massachusetts Rehabilitation
 Commission
 296 Boylston Street
 Boston, Massachusetts 02116

Mr. Steven A. Minter
 Commissioner, Massachusetts
 Dept of Public Welfare
 600 Washington Street
 Boston, Massachusetts 02111

Mr. John F. Mungovan
 Commissioner, Commission for
 the Blind
 39 Boylston Street
 Boston, Massachusetts 02116

Dr. Arthur Pappas
 Massachusetts Dept of Public
 Health
 488 Tremont Street
 Boston, Massachusetts 02116

MICHIGAN

Mr. Marvin E. Beekman
 Director, Special Education
 Services
 State Dept of Education
 Lansing, Michigan 48902

Maurice S. Belzen, M.D.
 Director of Public Health,
 Michigan Dept of Public Health
 3500 North Logan Street
 Lansing, Michigan 48914

Mr. R. Bernard Houston
 Director, State Dept of Social
 Services
 300 South Capitol
 Lansing, Michigan 48926

Mr. Ralf A. Packham
 Director, Division of Vocational
 Rehabilitation
 Dept of Education
 200 N. Capitol
 Lansing, Michigan 48904

Mr. Harold Payne
 Office of Services for the Blind
 State Dept of Social Services
 300 S. Capitol Avenue
 Lansing, Michigan 48913

R. Gerald Rice, M.D.
 Chief, Division of Services to
 Crippled Children
 Dept of Public Health
 252 Hollister Building
 Lansing, Michigan 48904

E. G. Yudashkin, M.D.
 Director, State Dept of Mental
 Health
 Lewis Cass Building
 Lansing, Michigan 48913

MINNESOTA

Mr. August W. Gehrke
 Assistant Commissioner for
 Rehabilitation and Special
 Education,
 State Board of Education
 1745 University Avenue
 St. Paul, Minnesota 55104

Mr. John C. Groos
 Director, Special Education
 Section
 State Dept of Education
 500 Cedar Avenue
 St. Paul, Minnesota 55101

Mr. Morris Hursh
 Commissioner, Minnesota Dept
 of Public Welfare
 Centennial Office Building
 658 Cedar Street
 St. Paul, Minnesota 55101

Warren R. Lawson, M.D.
 Secretary and Executive Officer,
 State Dept of Health
 717 Delaware Street, S.E.
 Minneapolis, Minnesota 55440

MISSISSIPPI

Mr. W. P. Bobo
 Administrative Director,
 Crippled Children's Service
 Dept of Education
 416 Woolfolk Building
 Jackson, Mississippi 39205

Mr. Jim L. Carballo
 Director, Division for the Blind
 P.O. Box 4872, Fondren Station
 Jackson, Mississippi 39216

Hugh B. Cottrell, M.D.
 State Health Officer,
 State Board of Health
 P.O. Box 1700
 Jackson, Mississippi 39205

Mildren Norval, M.D.
 Director, Crippled Children's
 Services
 State Dept of Public Welfare
 Centennial Building
 St. Paul, Minnesota 55101

Mr. C. Stanley Potter
 Director, State Services for
 the Blind and Visually
 Handicapped
 Dept of Public Welfare
 1745 University Avenue
 St. Paul, Minnesota 55104

Mr. J. T. Sarazin
 Director, Community Programs,
 Medical Services Division
 State Dept of Public Welfare
 Centennial Office Building
 St. Paul, Minnesota 55101

Mr. Ardo Wrobel
 Director, Mental Retardation
 Program
 State Dept of Public Welfare
 Centennial Office Building
 St. Paul, Minnesota 55101

Nina Goss-Moffitt, M.D.
 Director, Mental Health Services
 440 East Woodrow Wilson Avenue
 Jackson, Mississippi 39216

Mr. Seth Hudspeth
 Executive Secretary, Board of
 Trustees of Mental Institutions
 1404 Woolfolk Building
 Jackson, Mississippi 39201

Dorothy N. Moore, Ph.D.
 Interagency Commission on Mental
 Illness and Mental Retardation
 McGehee Office Annex, Suite J
 P.O. Box 16189
 Jackson, Mississippi 39206

MISSISSIPPI (Cont.)

Mr. John Webb
 Director, Division of Vocational
 Rehabilitation
 State Board of Education
 316 Woolfolk State Office Building
 P.O. Box 1698
 Jackson, Mississippi 39205

Mr. Herman K. White
 Supervisor, Special Education and
 Coordinator
 State Dept of Education
 Jackson, Mississippi 39205

Mr. Arthur Winstead
 Commissioner, State Dept of
 Public Welfare
 P.O. Box 4321, Fondren Station
 Jackson, Mississippi 39216

Frank Wiygul, M.D.
 Medical Director, Crippled
 Children's Service
 State Board of Health
 P.O. Box 14
 Jackson, Mississippi 39205

MISSOURI

Richard C. Arnold, M.D.
 Medical Director, Missouri
 Crippled Children's Services
 705 South 5th
 Columbia, Missouri 65201

Mr. Proctor N. Carter
 Director, Division of Welfare
 Dept of Public Health and Welfare
 State Office Building
 Jefferson City, Missouri 65101

Mr. Donald M. Cox
 Director, Special Education
 State Dept of Education
 P.O. Box 480
 Jefferson City, Missouri 65101

Herbert R. Domke, M.D.
 Division of Health
 Dept of Public Health and
 Welfare
 221 West High Street
 Jefferson City, Missouri 65101

Mr. V. S. Harshbarger
 Chief, Bureau for the Blind
 Division of Welfare
 Dept of Public Health and
 Welfare
 State Office Building
 Jefferson City, Missouri 65101

George A. Ulett, M.D.
 Director, Division of Mental
 Health
 Missouri Department of Public
 Health and Welfare
 722 Jefferson Street
 Jefferson City, Missouri 65101

MONTANA

John S. Anderson, M.D.
 Director, Montana Dept of Health
 and Environmental Sciences
 Cogswell Building
 Helena, Montana 59601

MONTANA (Cont.)

Mr. Theodore P. Carkulis
 Administrator, State Dept of
 Public Welfare
 515 S. Ewing Street
 P.O. Box 1723
 Helena, Montana 59601

Mr. Jack C. Carver
 State Director, Division of
 Vocational Rehabilitation
 State Board of Education
 507 Power Block
 Helena, Montana 59601

Mr. John Coey, Jr.
 Director, Division of Public
 Assistance
 State Dept of Public Welfare
 Helena, Montana 59601

Mr. Emil A. Honka
 Director, Division of Visual
 Service
 State Dept of Public Welfare
 Helena, Montana 59601

Mr. Edwin G. Kellner
 Director, State Dept of
 Institutions
 1236 East 6th Avenue
 Helena, Montana 59601

Mr. Jack Rudio
 Special Education
 Office of the Superintendent
 of Public Instruction
 State Capitol
 Helena, Montana 59601

NEBRASKA

Ms. Dorothy Bredemeyer
 Administrator, Services for
 Crippled Children
 2146 South 10th Street
 Lincoln, Nebraska 68502

Mr. Lawrence L. Graham
 Director, State Dept of Public
 Welfare
 1526 K Street, 4th Floor
 Lincoln, Nebraska

Mr. John B. Lamphere
 Administrator of Special
 Education,
 State Dept of Education
 233 South 10th Street
 Lincoln, Nebraska 68508

Mr. Dean McDermott
 Director, Division of Rehabili-
 tation Services for the
 Visually Impaired
 2104 O Street
 Lincoln, Nebraska 68510

Henry D. Smith, M.D.
 Director, Dept of Health
 State Capitol Building
 P.O. Box 94757
 Lincoln, Nebraska 68509

NEVADA

John H. Carr, M.D.
 State Health Officer,
 Division of Health
 State Dept of Health, Welfare
 and Rehabilitation
 201 South Fall Street
 Carson City, Nevada 89701

Mr. Larry Davis
 Director, Exceptional Pupil
 Education
 State Dept of Education
 Carson City, Nevada 89701

NEVADA (Cont.)

Mr. Marvin J. Flander
 Supervisor, Services to the
 Blind
 State Dept of Health, Welfare
 and Rehabilitation
 311 North Curry Street,
 Room 113
 Carson City, Nevada 89701

Robert J. McAllister, M.F.
 Administrator, Division of
 Mental Hygiene
 Nevada Dept of Health and
 Welfare
 P.O. Box 2460
 Reno, Nevada 89505

Mr. George E. Miller
 Administrator, State Welfare
 Division
 201 South Fall Street
 Carson City, Nevada

NEW HAMPSHIRE

Mary M. Atchison, M.D.
 Director, Division of Public
 Health
 State Dept of Health and
 Welfare
 61 South Spring Street
 Concord, New Hampshire 03301

Mr. Manfred F. Drewski
 Senior Consultant II, Special
 Education
 State Dept of Education
 64 North Main Street
 Concord, New Hampshire 03301

James W. Dykens, M.D.
 Director, Division of Mental
 Health
 105 Pleasant Street
 Concord, New Hampshire 03301

Mr. George E. Murphy
 Director, Division of Welfare
 State Dept of Health and
 Welfare
 1 Pillsbury Street
 Concord, New Hampshire 03301

Mr. Gerald J. Zeiller
 Commission of Health and Welfare,
 State Dept of Health and Welfare
 1 Pillsbury Street
 Concord, New Hampshire 03301

NEW JERSEY

James R. Cowan, M.D.
 State Commissioner of Health,
 State Dept of Health
 P.O. Box 1540
 Trenton, New Jersey 08625

Mr. Irving J. Engelman
 Director, Division of Public
 Welfare
 State Dept of Institutions
 and Agencies
 P.O. Box 1627
 Trenton, New Jersey 08625

NEW JERSEY (Cont.)

Mr. Joseph Kohn
 Executive Director, Commission
 for the Blind
 State Board of Control
 Dept of Institutions and
 Agencies
 1100 Raymond Boulevard
 Newark, New Jersey 07102

Maurice G. Kott, Ph.D.
 Director, Division of Mental
 Retardation
 State Dept of Institutions and
 Agencies
 P.O. Box 1237
 Trenton, New Jersey 08625

Mr. Lloyd W. McCorkle
 Commissioner, Dept of Institutions
 and Agencies
 P.O. Box 1237
 135 West Hanover Street
 Trenton, New Jersey 08625

Morton L. Poyas, M.D.
 Program Coordinator for Crippled
 Children's Services
 State Dept of Health
 P.O. Box 1540
 Trenton, New Jersey 08625

Mr. Daniel Ringelheim
 Deputy Assistant Commissioner,
 Branch of Special Education
 and Pupil Personnel Services
 State Dept of Education
 225 West State Street
 Trenton, New Jersey 08625

Mr. Arthur J. Sinclair
 Director, New Jersey Rehabili-
 tation Commission
 Dept of Labor and Industry
 John Fitch Plaza
 Trenton, New Jersey 08625

NEW MEXICO

Stuart W. Adler, M.D.
 Medical Director, Crippled
 Children's Services
 P.O. Box 2348
 Santa Fe, New Mexico 87501

Mr. Lawrence C. Brown
 Director, Social and Rehabilitation
 Services Division
 Health and Social Services Dept
 P.O. Box 2348
 Santa Fe, New Mexico 87501

Mr. Belarmino Giron
 Director, Dept of Hospitals and
 Institutions
 Lamy Building
 Sante Fe, New Mexico 87501

Mr. Elie S. Gutierrez
 Director, Division of Special
 Education
 State Dept of Education
 300 Don Gaspar Avenue
 Santa Fe, New Mexico 87501

Mr. Richard W. Heim
 Executive Director,
 New Mexico Dept of Health and
 Social Services
 P.O. Box 2348
 Santa Fe, New Mexico 87501

Dr. Robert A. Swanson
 Director, Division of Vocational
 Rehabilitation
 State Board of Vocational
 Education
 P.O. Box 1830
 Santa Fe, New Mexico 87501

NEW YORK

Mr. John A. Baldwin
 Director, Commission for the
 Blind and Visually
 Handicapped
 New York State Dept of Social
 Services
 1450 Western Avenue
 Albany, New York 12203

Hollis S. Ingraham, M.D.
 Commissioner of Health,
 State Dept of Health
 84 Holland Avenue
 Albany, New York 12208

Mr. Adrian Levy
 Associate Commissioner,
 Office of Vocational
 Rehabilitation
 State Education Dept
 99 Washington Avenue
 Albany, New York 12210

Alan D. Miller, M.D.
 Commissioner, State Dept of
 Mental Hygiene
 44 Holland Avenue
 Albany, New York 12208

Mr. Thomas A. Patterson
 Superintendent, State School
 for the Blind
 Batavia, New York 14020

Mr. Raphael F. Simches
 Assistant Director, Division
 for Handicapped Children
 State Dept of Education
 Albany, New York 12224

Mr. George K. Wyman
 Commissioner, New York State
 Dept of Social Services
 1450 Western Avenue
 Albany, New York 12203

NORTH CAROLINA

Ruth Burroughs, M.D.
 Chief, Crippled Children's
 Section
 State Board of Health
 P.O. Box 2091
 Raleigh, North Carolina 27602

Mr. Clifton Craig
 Commissioner,
 State Dept of Social Services
 P.O. Box 2599
 Raleigh, North Carolina 27602

Mr. Theodore R. Drain
 Director, Division for Exceptional
 Children
 State Dept of Public Instruction
 Raleigh, North Carolina 27602

Mr. Wilbur E. Early
 Executive Director,
 State Commission for the Blind
 P.O. Box 2658
 Raleigh, North Carolina 27602

Eugene A. Hargrove, M.D.
 Commissioner, State Dept of
 Mental Health
 325 North Salisbury Street*
 P.O. Box 26237
 Raleigh, North Carolina 27611

Jacob Koomen, Jr., M.D.
 Secretary and State Health
 Director,
 State Board of Health
 225 North McDowell Street
 Raleigh, North Carolina 27602

Mr. Claude A. Myer
 Administrator, Division of
 Vocational Rehabilitation
 Dept of Human Resources
 305 1/2 W. Martin Street
 Raleigh, North Carolina 27602

NORTH DAKOTA

James R. Amos, M.D.
 State Health Officer,
 State Dept of Health
 State Capitol
 Bismarck, North Dakota 58501

Paul W. Freise, M.D.
 Medical Director, Crippled
 Children's Services
 Public Welfare Board of
 North Dakota
 Bismarck, North Dakota 58501

Mr. Leslie O. Ovre
 Executive Director, Dept of
 Social Services
 Capitol Building
 Bismarck, North Dakota 58501

Ms. Janet M. Smaltz
 Director, Special Education
 State Dept of Public Instruction
 Bismarck, North Dakota 58501

OHIO

Elizabeth R. Aplin, M.D.
 Medical Director,
 Bureau of Crippled Children's
 Services
 State Dept of Public Welfare
 408 East Town Street
 Columbus, Ohio 43215

Mr. S. J. Bonham, Jr.
 Director, Division of Special
 Education
 State Dept of Education
 3201 Alberta Street
 Columbus, Ohio 43204

John W. Cashman, M.D.
 Director of Health,
 Ohio Dept of Health
 450 East Town Street
 Columbus, Ohio 43216

Kenneth Gaver, M.D.
 Director, Dept of Mental Hygiene
 and Correction
 65 South Front Street
 Columbus, Ohio

Roger M. Gove, M.D.
 Commissioner, Division of Mental
 Retardation
 Dept of Mental Hygiene and
 Correction
 State Office Building
 Columbus, Ohio 43215

Mr. John E. Hansan
 Director, State Dept of Public
 Welfare
 408 East Town Street
 Columbus, Ohio 43215

J. Wylie McGough, M.D.
 Commissioner, Division of Mental
 Hygiene
 Dept of Mental Hygiene and
 Correction
 State Office Building
 Columbus, Ohio 43215

Mr. Denver L. White
 Administrator, Ohio Rehabilita-
 tion Services Commission
 4656 Heaton Road
 Columbus, Ohio 43229

OKLAHOMA

R. Leroy Carpenter, M.D.
 Commissioner of Health,
 State Dept of Health
 3400 North Eastern
 Oklahoma City, Oklahoma 73105

William J. Craig, M.D.
 Supervisor, Crippled Children's
 Unit
 Dept of Institutions, Social and
 Rehabilitation Services
 Oklahoma City, Oklahoma 73105

OKLAHOMA (Cont.)

Hayden Donahue, M.D.
 Director, State Dept of Mental
 Health
 State Capitol Building
 Oklahoma City, Oklahoma 73105

Mr. Maurice P. Walraven
 Director of Special Education,
 State Dept of Education
 State Capitol Building
 Oklahoma City, Oklahoma 73105

Mr. L. E. Rader
 Director, State Dept of Insti-
 tutions, Social and Rehabili-
 tative Services
 P.O. Box 25352
 Oklahoma City, Oklahoma 73125

OREGON

Kenneth D. Gaver, M.D.
 Administrator, Mental Health
 Division
 2570 Center Street, N.E.
 Salem, Oregon 97310

Edward Press, M.D.
 State Public Health Officer,
 State Board of Health
 1400 Southwest Fifth Avenue
 Portland, Oregon 97201

Mr. Andrew F. Juras
 Administrator, State Public
 Welfare Division
 422 Public Service Building
 Salem, Oregon 97310

Mr. Norm Silver
 Administrator, State Vocational
 Rehabilitation Division
 Dept of Human Resources
 680 Cottage Street, N.E.
 Salem, Oregon 97310

Mr. Mason D. McQuiston
 Director of Special Education,
 Oregon Board of Education
 Salem, Oregon 97310

Richard L. Sleeter, M.D.
 Director, Crippled Children's
 Division
 University of Oregon Medical
 School
 3181 S. W. San Jackson Park
 Road
 Portland, Oregon 97201

Mr. Robert L. Pogorelc
 Administrator, State Commission
 for the Blind
 535 S.E. 12th Avenue
 Portland, Oregon 97214

PENNSYLVANIA

Gordon Allan, M.D.
 Director, Division of Maternal and
 Child Health and Crippled
 Children's Services
 407 South Cameron Street
 Harrisburg, Pennsylvania 17120

Mr. Ralph E. Beistline
 Pennsylvania Bureau of Visually
 and Physically Handicapped
 Dept of Public Welfare
 330 Capital Associates Bldg.
 P.O. Box 2675
 Harrisburg, Pennsylvania 17120

PENNSYLVANIA (Cont.)

Donald H. Jolly, M.D.
 Commissioner, Office of Mental
 Retardation
 State Dept of Public Welfare
 Harrisburg, Pennsylvania 17120

Mr. Lee V. Kebach
 Director, Bureau of Vocational
 Rehabilitation
 Dept of Labor and Industry
 Labor and Industry Bldg.
 Harrisburg, Pennsylvania 17120

Mr. William F. Ohrtman
 Director, Bureau of Special
 Education, Dept of Education
 P.O. Box 911
 Harrisburg, Pennsylvania 17126

J. Finton Speller, M.D.
 Secretary of Health,
 Pennsylvania Dept of Health
 P.O. Box 90
 Health and Welfare Building
 Harrisburg, Pennsylvania 17120

Deputy Secretary for Mental
 Health and Retardation
 Office of Mental Health
 Dept of Public Welfare
 Harrisburg, Pennsylvania 17120

RHODE ISLAND

Mr. John P. Affleck
 Director, State Dept of Social and
 Rehabilitative Services
 600 New London Avenue
 Cranston, Rhode Island 02920

Joseph E. Cannon, M.D.
 Director, Rhode Island Dept of
 Health
 Davis Street
 Providence, Rhode Island 02908

Mr. Edward Carley
 Chief, Division of Vocational
 Rehabilitation
 Social and Rehabilitative Services
 40 Fountain Street
 Providence, Rhode Island 02903

Mr. Francis B. Conley
 Coordinator, Special Education
 State Dept of Education
 Roger Williams Building
 Providence, Rhode Island 02908

Mr. E. Lyman D'Andrea
 Administrator, Division of
 Services for the Blind
 Social and Rehabilitative
 Services
 46 Aborn Street
 Providence, Rhode Island 02903

Charles C. Goodman, M.D.
 Assistant Director, Mental Health
 State Dept of Mental Health,
 Retardation and Hospitals
 600 New London Avenue
 Cranston, Rhode Island 02920

Jean M. Maynard, M.D.
 Division of Child Health Services
 State Dept of Health
 Davis Street
 Providence, Rhode Island 02908

Mr. Miles B. Santamour
 Assistant Director, Retardation
 State Dept of Mental Health,
 Retardation and Hospitals
 600 New London Avenue
 Cranston, Rhode Island 02920

RHODE ISLAND (Cont.)

Mr. Anthony P. Travisono
 Director, Dept of Mental Health,
 Retardation and Hospitals
 600 New London Avenue
 Cranston, Rhode Island 02920

SOUTH CAROLINA

Kenneth E. Aycock, M.D.
 State Health Officer,
 State Board of Health
 J. Marion Sims Building
 Columbia, South Carolina 29201

Dr. Dill D. Beckman
 Commissioner, Vocational
 Rehabilitation Dept
 State Agency of Vocational
 Rehabilitation
 400 Wade Hampton State Office
 Bldg.
 Columbia, South Carolina 29201

Mr. W. Owens Corder
 Director, Office of Programs for
 the Handicapped
 State Dept of Education
 Room 309, Rutledge Bldg.
 Columbia, South Carolina 29201

Dr. F. L. Crawford
 Executive Director, Commission
 for the Blind
 1400 Main Street
 Columbia, South Carolina 29201

SOUTH DAKOTA

Mr. Howard H. Hanson
 Director, South Dakota Service
 to Visually Impaired
 222 East Capitol Avenue
 Pierre, South Dakota 57501

Robert H. Hayes, M.D.
 State Dept of Health
 State Capitol
 Pierre, South Dakota 57501

Dr. R. Archie Ellis
 Director, State Dept of Public
 Welfare
 P.O. Box 1520
 Columbia, South Carolina 29202

William S. Hall, M.D.
 Commissioner, South Carolina
 Dept of Mental Health
 2414 Bull Street
 Columbia, South Carolina 29201

James E. Padgett, M.D.
 Program Director, Bureau of
 Maternal and Child Care and
 Division of Crippled
 Children's Care
 State Board of Health
 Columbia, South Carolina 29201

Mr. Ben F. Hins
 Director, Division of Vocational
 Rehabilitation
 State Board of Education
 200 West Pleasant Drive
 Pierre, South Dakota 57501

SOUTH DAKOTA (Cont.)

Mr. Robert L. Huckins
 Director, State Dept of Public
 Instruction
 Division of Public Personnel
 Services
 804 North Euclid
 Pierre, South Dakota 57501

Mr. John E. Madigan
 Director, Dept of Public Welfare
 State Office Building
 Pierre, South Dakota 57501

Mr. Norman Van Klompenburg
 Director, Commission of Mental
 Health and Mental Retardation
 116 North Euclid, Suite 6
 Pierre, South Dakota 57501

TENNESSEE

Eugene W. Fowinkle, M.D.
 Commissioner, Dept of Public
 Health
 Cordell Hull Building
 Sixth Avenue North
 Nashville, Tennessee 37219

Ms. Elaine Parker
 Director, Services for the Blind
 State Dept of Public Welfare
 304 State Office Building
 Nashville, Tennessee 37219

Mr. Fred E. Friend
 Commissioner, State Dept of
 Public Welfare
 410 State Office Building
 Nashville, Tennessee 37219

C. Richard Treadway, M.D.
 Commissioner, Dept of Mental
 Health
 Cordell Hull Building, Room 300
 Nashville, Tennessee 37219

Vernon L. Johnson
 Coordinator, Special Education
 State Dept of Education
 134 Cordell Hull Building
 Nashville, Tennessee 37219

TEXAS

William S. Brumage, M.D.
 Director and Chief, Special
 Health Services
 Division of Crippled Children's
 Services
 State Dept of Health
 1100 West 49th Street
 Austin, Texas 78756

Mr. Burton G. Hackney
 Commissioner, State Dept of
 Public Welfare
 John H. Reagan Building
 Austin, Texas 78701

Mr. Jess Irwin, Jr.
 Commissioner, Texas Rehabilitation
 Commission
 1301 W. 38th Street
 Austin, Texas 78705

TEXAS (Cont.)

Mr. Don L. Partridge
 Director, Division of Special
 Education
 Texas Education Agency
 201 East 11th Street
 Austin, Texas 78711

J. E. Peavy, M.D.
 Commissioner of Health,
 State Dept of Health
 1100 West 49th Street
 Austin, Texas 78756

Mr. Burt L. Risley
 Executive Director, State Com-
 mission for the Blind
 P.O. Box 12886
 Austin, Texas 78711

David Wade, M.D.
 Commissioner, Texas Dept of
 Mental Health and Mental
 Retardation
 P.O. Box 12668, Capital Station
 Austin, Texas 78711

UTAH

Paul R. Ensign, M.D.
 Director, Maternal and Child
 Health
 State Dept of Social Services
 44 Medical Drive
 Salt Lake City, Utah 84113

Wilfred H. Higashi, Ph.D.
 Director, Division of Mental
 Health
 Utah Dept of Social Services
 520 East Fourth St.
 Salt Lake City, Utah 84102

Dr. Harvey C. Hirschi
 Administrator, Division of
 Rehabilitation Services
 State Board of Vocational
 Education
 136 East South Temple
 Salt Lake City, Utah 84111

Mr. Richard P. Lindsay
 Executive Director, Utah State
 Dept of Social Services
 221 State Capitol
 Salt Lake City, Utah 84114

Lyman J. Olsen, M.D.
 Director, State Division of
 Health
 Utah Dept of Social Services
 44 Medical Drive
 Salt Lake City, Utah 84113

Mr. R. Elwood Pace
 Coordinator, Special Education
 Programs
 Utah State Board of Education
 136 East South Temple
 Salt Lake City, Utah 84111

VERMONT

Robert B. Aiken, M.D.
 State Health Commissioner,
 Vermont Dept of Health
 115 Colchester Avenue
 Burlington, Vermont 05401

Joan Babbott, M.D.
 Director, Division of Child
 Health Services
 Dept of Health
 115 Colchester Avenue
 Burlington, Vermont 05401

VERMONT (Cont.)

Mr. Joseph W. Betit
 Commissioner, State Dept of
 Social Welfare
 Montpelier, Vermont 05602

Ms. Virginia Cole
 Director, Division of Services
 for the Blind and Visually
 Handicapped
 Dept of Rehabilitation
 128 State Street
 Montpelier, Vermont 05602

Ms. Jean S. Garvin
 Director, Special Educational
 and Pupil Personnel Services
 State Dept of Education
 Montpelier, Vermont 05602

Mr. Richard W. Hill
 Director, Vocational Rehabilita-
 tion Division
 Dept of Rehabilitation
 Agency of Human Services
 79 Main Street
 Montpelier, Vermont 05602

Jonathan P.A. Leopold, M.D.
 Commissioner, Vermont Dept of
 Mental Health
 State Office Building
 Montpelier, Vermont 05602

VIRGINIA

William S. Allerton, M.D.
 Commissioner, State Dept of
 Mental Hygiene and Hospitals
 P.O. Box 1797
 Richmond, Virginia 23214

Ms. Eula Jane Armstrong
 Chief, Bureau of Assistance and
 Service Programs
 State Dept of Welfare and
 Institutions
 429 South Belvidere Street
 Richmond, Virginia 23220

Mr. Otis L. Brown
 Director, State Dept of Welfare
 and Institutions
 429 S. Belvidere Street
 Richmond, Virginia 23220

Mr. William T. Coppage
 Director, Virginia Commission
 for the Visually Handicapped
 3003 Parkwood Avenue
 Richmond, Virginia 23221

W. R. Ferguson, M.D.
 Director, Bureau of Crippled
 Children
 Dept of Health
 109 Governor Street
 Richmond, Virginia 23221

Mr. S. P. Johnson, Jr.
 Director, Division of Elementary
 and Special Education
 State Dept of Education
 Richmond, Virginia 23216

Mr. Don W. Russell
 Commissioner, State Dept of
 Vocational Rehabilitation
 4615 West Broad Street
 P.O. Box 11045
 Richmond, Virginia 23230

Mack I. Shanholtz, M.D.
 State Health Commissioner,
 State Dept of Health
 109 Governor Street
 Richmond, Virginia 23219

WASHINGTON

John A. Beare, M.D.
Division of Health
Public Health Bldg.
Olympia, Washington 98501

Dr. Jerome Dunham
Chief, Services for the Blind
Dept of Social and Health
Services
3411 South Alaska Street
Seattle, Washington 98118

Mr. Peter Jamero
Vocational Rehabilitation Services
Division
Dept of Social and Health Services
P.O. Box 1788
Olympia, Washington 98501

H. Wallace Lane, M.D.
State Dept of Health and Health
Services
Public Health Building
Olympia, Washington 98501

Ms. Gladys Randall McCorkhill
Chief, Office of Assistance
Eligibility Division of Public
Assistance
P.O. Box 1162
Olympia, Washington 98501

Mr. John P. Mattson
Director, Dept of Special Services
P.O. Box 527
Olympia, Washington 98504

Robert Murphy, M.D.
Supervisor, Dept of Social and
Health Services
Public Health Bldg.
Olympia, Washington 98502

Robert Sherer, M.D.
Chief, Office of Mental Health
Division of Institutions
P.O. Box 768
Olympia, Washington 98501

WEST VIRGINIA

Newman H. Dyer, M.D.
State Director of Health
State Dept of Health
1800 Washington Street, East
Charleston, West Virginia 25305

Mr. Roger P. Elser, Director
Division of Special Education
West Virginia Dept of Education
Bldg. B, Unit 6, Room 315
State Capitol
Charleston, West Virginia 25305

Mr. Edwin F. Flowers
Commissioner, Dept of Welfare
State Office Bldg. B
1900 Washington Street, East
Charleston, West Virginia 25305.

Mr. Thorold S. Funk
Director, Division of Vocational
Rehabilitation
State Board of Vocational
Education
2019 Washington, East
Charleston, West Virginia 25305

Mildred Mitchell-Bateman, M.D.
Director, State Dept of Mental
Health
1800 Washington Street, East
Charleston, West Virginia 25305

WISCONSIN

Leonard J. Ganser, M.D.
 Administrator, Division of
 Mental Hygiene
 State Dept of Health and
 Social Services
 State Office Building
 Madison, Wisconsin 53702

George H. Handy, M.D.
 Administrator, Division of
 Health
 State Dept of Health and
 Social Services
 P.O. Box 309
 Madison, Wisconsin 53701

Mr. John W. Melcher
 Assistant State Superintendent,
 State Dept of Public Instruction
 126 Langdon Street
 Madison, Wisconsin 53702

Mr. Wilbur J. Schmidt
 Secretary, State Dept of Health
 and Social Services
 State Office Building
 Madison, Wisconsin 53702

Horace Tenney, M.D.
 Bureau for Crippled Children
 State Dept of Public Instruction
 126 Langdon Street
 Madison, Wisconsin 53702

Mr. Adrian E. Towne
 Administrator, Division of
 Vocational Rehabilitation
 State Dept of Health and Social
 Services
 1 West Wilson Street, Room 685
 Madison, Wisconsin 53702

WYOMING

Mr. L. Owen Barnett
 Dept of Vocational
 Rehabilitation
 State Office Building
 Cheyenne, Wyoming

Lawrence J. Cohen, M.D.
 Administrator, Wyoming Dept of
 Public Health and Medical
 Services
 State Office Building
 Cheyenne, Wyoming 82001

Mr. Lamar Gordon
 Office of Exceptional Children
 State Dept of Education
 Cheyenne, Wyoming

Mr. John H. Morros
 Division of Public Assistance
 and Social Services
 State Office Building
 Cheyenne, Wyoming 82001

Mr. Cone J. Munsey
 Director, Mental Health and
 Mental Retardation Services
 Division of Health and Medical
 Services
 State Office Building
 Cheyenne, Wyoming 82001

Appendix D

STATE SURVEY QUESTIONNAIRES

O.M.B. No. 85-S72018
Approval expires FEB. 1973

BRIEF OUTLINE OF STUDY ON SERVICES FOR THE HANDICAPPED

A comprehensive study of services for handicapped youth is being conducted by The Rand Corporation under sponsorship of the U.S. Department of Health, Education, and Welfare. Initiated in February 1972, the study is concerned with programs for persons up to 21 years of age who are mentally or physically impaired. The purpose of the study is to provide information that will aid in planning the allocation of Federal resources to provide improved assistance and services for handicapped youth.

The study has two major components. The first (related to the two enclosed questionnaires) is to obtain an estimate of current allocations of Federal and State resources provided for handicapped youth, and to determine who receives what type of assistance or service. The second major component concerns the benefits, effectiveness and impact of government assistance and services on the quality of life of the aurally or visually handicapped. Additionally, the second component may eventually serve as a prototype for subsequent studies of assistance and services to other categories of handicapped persons.

The first step in the study is to acquire information on the actual dimensions of programs for the handicapped, particularly: budgetary data, types of services rendered, the numbers and types of persons receiving assistance. As analysts, we are aware of considerable semantic uncertainties and definitional overlaps that exist regarding various types of handicapped as well as various types of services rendered to them. We shall not concentrate efforts—at least not at the outset of the study—on developing new and stringent definitions. This is because the categories so created, be they of the handicapped or the services rendered to them, might then not coincide with the categories in which statistics or budgets are readily available. (Conceivably, one of the by-products of the study will be new sets of generally applicable definitions both for categories of handicapped and services received by them.)

Two questionnaires will be mailed to officials in all fifty states and serve as instruments to provide the initial data base—Questionnaire I is designed to provide an *overview* of aid to the handicapped in each state, and Questionnaire II is designed to provide information on *individual programs*. Ten copies of Questionnaire II are enclosed on the assumption that nearly every state agency or department will have ten or less major programs to be described in the areas of providing assistance or services to handicapped persons, excluding those programs that serve only persons over 21 years of age. [A program is used here to mean an organizational subdivision of the agency or a budgetary subdivision on which separate, specific data are available.] Please call us for additional copies if you need more than ten.

In view of the variation in definitions and the wide differences in categories used in book-keeping and statistical analyses in the field of services for the handicapped, we do not expect to eliminate all ambiguity from our findings or to provide hard figures for all study categories. Therefore, those in State government filling out the questionnaires should try to furnish *estimates* where they have no specific figures, and do their reporting on activities and the type of handicapped in terms of such categories as happen to be available—with a word of explanation as to what the categories contain. As interpretation of terms will vary from agency to agency, a considerable divergence in responses and the need for flexibility in the analysis of the results is anticipated.

In case these general comments do not dispel remaining doubts and questions, Dr. James S. Kakalik, director of the study at The Rand Corporation, will be able to provide further information. (Please call collect—213-393-0411.)

Questionnaire I: OVERVIEW OF ASSISTANCE TO HANDICAPPED YOUTH

State: _____

Name of Agency or Department: _____

Person Answering This Questionnaire:

Name: _____

Address: _____

Title: _____

Telephone: (Area Code ()- _____

Extension: _____

Categories of handicap of interest in these questionnaires include deaf, hard of hearing, blind, partially sighted, crippled or other health impaired, speech impaired, learning disabled, mentally retarded, emotionally disturbed, multiple handicapped, and any other categories of physical or mental handicap that your agency assists. Categories of assistance or service include prevention of handicapping conditions; identification, direction or referral of handicapped persons; medical treatment; psychological counseling; income maintenance; personal care; general education; specialized training in areas such as mobility or speech; vocational training; job placement; sensory aids; equipment; recreation or social activity; training professional service personnel; and research on any of the previously mentioned types of assistance or services.

- 1.** What programs are in operation in your State under your agency's or department's direction in the areas of providing assistance or services to handicapped persons, excluding those programs that serve only persons over 21 years of age? By the term program we mean an organizational or budgetary subdivision of your agency on which separate specific data are available. In lieu of a brief description of each program, you may wish to append descriptive booklets or other prepared materials. Illustrative examples of programs are: an education agency's residential schools for handicapped children or transportation of students; a rehabilitation agency's sheltered workshops or income maintenance while undergoing vocational training; a health agency's vaccination program or purchases of sensory aids; or a social welfare agency's payments to the blind or counseling of handicapped persons. These examples are not exhaustive, but merely illustrative of the kinds of programs for which we would like you to supply information.

NAME OF PROGRAM

BRIEF DESCRIPTION OF PROGRAM

a.	_____	_____

b.	_____	_____

c.	_____	_____

d.	_____	_____

e. _____

f. _____

g. _____

h. _____

i. _____

j. _____

Please attach your answers to the following questions on separate pages.

- 2.** Is there any statistical or other information in this area that you think would be of relevance in a study of such programs? We would appreciate receiving all available material that describes each of your programs, including (1) enabling legislation (State and/or local), (2) annual reports, (3) special reports, (4) descriptive booklets, (5) budget materials, (6) reports you send to other agencies, (7) research reports on any type of assistance, service, or handicap, and (8) your state's legal or regulatory definitions of handicaps.*

- 3.** Would you please summarize any particular problem areas in federal or state assistance-or-services-to-the handicapped programs?

- 4.** Would you care to make some suggestions for improvements in the area of assistance or services to handicapped youth?

*Rand will pay the cost of reproduction and postage if necessary for any of these materials.

Questionnaire II: INDIVIDUAL PROGRAMS FOR ASSISTANCE TO THE HANDICAPPED

Please complete one copy of this questionnaire for each of the individual programs listed in Questionnaire I.

Name of Program: _____

Is there any statistical or other information on this program that you think would be of relevance in this study? We would appreciate receiving any available material that describes this program, including (1) enabling legislation (State and/or local), (2) annual reports, (3) special reports, (4) descriptive booklets, (5) budget materials, (6) reports you send to other agencies, (7) research reports on any type of assistance, service or handicap, and (8) your state's legal or regulatory definitions of handicaps.*

1. What was the budget for this program in fiscal year 1971?

SOURCE OF FUNDS	AMOUNT
Federal	_____
State	_____
Local	_____
Private	_____
Total	_____

*Rand will pay the cost of reproduction and postage if necessary.

- 2.** What does the money buy? Please provide as much information as possible,** breaking down these general categories for a recent one-year period, preferably FY 1971:

BUDGET ITEM	APPROXIMATE BUDGET
(a) State Personnel	_____
Total Number of State Personnel _____	
Number of Professionals _____	
(A.B. degree or higher required) _____	
(b) Training of Personnel to Serve the Handicapped	_____
Total Number of persons completing training _____	
Number of professionals completing training _____	
(c) Research	_____
(d) Payments to private organizations or professionals for services to the handicapped	_____
(e) Direct payments to local or regional public agencies	_____
(f) Direct payments to the handicapped	_____
(g) Educational supplies for the handicapped	_____
(h) Sensory aids and prosthetic devices	_____
(i) Drugs and medical supplies (other than sensory aids and prosthetic devices)	_____
(j) Capital expenditures for construction of physical plant	_____
(k) Maintenance of physical plant	_____
(l) Other budget categories used by your agency (please describe)	_____
_____	_____
_____	_____

**If exact information is not available, we would appreciate a reasonable estimate. Please indicate numbers that are estimated with an asterisk (*).

- 3.** What categories of assistance or service are provided or funded by this program? How is each category defined? For example, kinds of services that might be provided include:

ASSISTANCE OR SERVICE	ILLUSTRATIVE EXAMPLES
Prevention of Handicapping Conditions	Prenatal and maternal care; preventive medical programs
Identification	Mass screening programs
Direction or Referral	Diagnostic work-ups; individual comprehensive health planning; matching individuals with services provided
Medical or Surgical Treatment	Stapedectomy; chemotherapy; physical therapy
Psychological Counseling	Counseling child; counseling family
Income Maintenance	
Personal Care	Visiting nurse programs; residential care programs
Specialized Training	Mobility training for the blind; speech therapy
Vocational Training	Basic work habit training; occupational training
Job Placement	Employer education; placement of individuals
Sensory aids and/or Prosthetic Devices	Hearing aids, glasses, visual image enhancement devices
Recreational or Social Activities	Field trips, athletic programs
Training Service Personnel	Paraprofessionals, specialized MD's
Research	On any or all of above assistance or services

We realize that your data and program may be organized differently and ask that you describe the categories of assistance or services your program offers.

d. Sex: How many of those served, by state personnel and/or personnel in other organizations funded by this program, are in each category?

	NUMBER SERVED	
	TOTAL	UNDER AGE 22
Female	_____	_____
Male	_____	_____

e. Race: How many of those served, by state personnel and/or personnel in other organizations funded by this program, are in each category?

	NUMBER SERVED	
	TOTAL	UNDER AGE 22
Black	_____	_____
White	_____	_____
Spanish Surname	_____	_____
Other	_____	_____

f. Economic Status: What groups are served? How many persons in each group are served by state personnel and/or personnel in other organizations funded by this program?

FAMILY INCOME RANGE	NUMBER SERVED	
	TOTAL	UNDER AGE 22
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

5. How is contact established between the handicapped youth and the organizations directly providing the assistance or services funded by this program? Please estimate the percentage from:

SOURCE	PERCENTAGE
Physician referral?	_____
Welfare referral?	_____
Rehabilitation referral?	_____
Teacher's referral?	_____
Mass screening program?	_____
Parent initiated?	_____
Other (describe)	_____
_____	_____
_____	_____
_____	_____

APPENDIX E

INTERVIEW SURVEY OF PARENTS OF HANDICAPPED YOUTH

INTRODUCTION

To evaluate current and alternative future policies comprehensively for service to auditorially and visually handicapped youth, we are collecting information from both the providers and the recipients of service. Part of an ongoing study, the results of which will be given in a subsequent report, the personal interview survey described in this appendix is directed at parents in families receiving services for their handicapped youth.

An extensive survey questionnaire is utilized in an attempt to get the "target population viewpoint" in a number of areas, for example:

- Needs for services;
- Deficiencies in single services or in the mix of services offered;
- Problems with the agency, mechanism, or personnel providing services;
- Goals and objectives of parents of handicapped youth;
- Relative importance of each type of service in relation to the others;
- Past, present, and projected future impact of various services on the general quality of life of handicapped children;
- Impact of various services on physical skills, social skills, psychological states, financial states, etc.;
- Suggestions for service and program improvement.

SURVEY DESIGN

The survey involves administering an extensive questionnaire to a sample of approximately 100 families of children with impaired vision or hearing. The sample size was dictated by the need to have a reasonable number of children in each subclassification (state, age, handicap) consistent with budget and time constraints on this research. Since the information generated by the survey is intended to develop insight rather than to test hypotheses, we felt that an interviewer knowl-

edgeable in the subject area would be able to develop useful information from the replies to semi-open-ended questions obtained from a relatively small sample. Families, rather than the handicapped children themselves, are being interviewed because we felt that youth, especially very young persons, might react unfavorably to being singled out as handicapped, impaired, or "different" in any fashion, or to the implied criticism of those providing service. In the case of older youth, perhaps living away from home, interviews are sometimes being conducted with the handicapped person rather than the family, but these are the exceptions.

As one source of families, we contacted staff members of agencies with whom the project staff had dealt in the earlier phase of the study. Although this approach excludes respondents who are not being served by some agency, this is not a severe drawback. The survey is designed to tap attitudes and opinions concerning the system of services presently offered, and those currently in contact with the system are more likely to have accurate memory and detailed opinion about it. We sought referrals from an assortment of *types* of agencies serving the handicapped, including health agencies, schools (both those serving the handicapped exclusively and regular schools with programs for the vision or hearing impaired), welfare agencies, and rehabilitation programs. We are also attempting to reach persons the government does not serve by requesting referrals from private clinics and physicians, as well as from associations of the handicapped. We explicitly requested names of parents whose children were representative of the handicapped youth served, and have requested *three* names for each interview to be conducted, thus making it more difficult for the agency to select "stars," and giving the interviewer some opportunity to choose families from areas of varying ethnic and economic characteristics.

Other strategies designed to ensure a fairly wide range of responses to the questionnaire include a threefold breakdown of the sample—by age, handicap, and geographic location. Four age groups are separated (0-5 years old, 6-12, 13-17, and 18-21). The divisions correspond roughly to life stages—preschool, elementary school, intermediate school, and young adults.

The sample is also broken down by handicap: blind and partially-sighted for the visually handicapped; deaf and hard-of-hearing for the auditorially handicapped. Thus, both severity and type of handicap are controlled. Preliminary results of the survey confirmed our hypothesis that different kinds and amounts of services are offered the more severely impaired.

Finally, the sample includes families from three states—California, Massachusetts, and Wyoming. These states were selected from the five in which members of the project had interviewed agency personnel because the states have diverse types of service systems about which we are knowledgeable, and because the contacts we had made provided a basis for requesting referrals. The particular states chosen provide some variation along an urban-rural dimension. Within California, interviews will be conducted in the San Francisco and San Diego areas as well as around Los Angeles.

Only about 30 families will be interviewed in each state; thus the 4×4 matrix obtained by subdividing into age and handicap categories permits only two families of each type of child to be interviewed. Such a sample is too small to use for other than heuristic purposes. Since actually drawing a random sample would be difficult

and time-consuming for the referring agencies and would add little to the value of observations generated by the survey, the agencies were asked to use any convenient method of selecting families in the categories specified for the survey.

QUESTIONNAIRE DESIGN

The questionnaire was developed after examining, as models, several other instruments designed to assess the service needs of handicapped persons (not, as in the present study, young persons only). Unlike the models, however, Rand's questionnaire is not rigidly structured, using mostly open-ended questions. Since the survey is intended to serve a heuristic as well as an information-gathering function, open-ended questions seemed more useful. They also permit the interviewer to more easily adapt the scheduled questions to each respondent and to probe for the anecdotal material desired.

The questionnaire is prefaced by a statement of purpose—of The Rand Corporation study and of the survey—and a few paragraphs explaining what is meant by such terms as "service" and "agency." The schedule is organized around ten basic need areas: medical treatment; special equipment; personal care; education; vocational training; job placement; counseling; transportation; recreation; and financial assistance. Past, present, and projected future needs are elicited. Each specific agency either in use or used previously is the subject of a series of specific questions to determine the client's opinion of its good and bad effects.

A second section of the interview focuses on how the client sees the service system as a whole—what unmet needs exist, what difficulties in obtaining information or assistance have been felt. Respondents are also asked to rate each service's effect on quality of life, both per se and in relation to other service needs. Attitudes toward alternative roles for government as purveyor of services are also explored in an attempt to gain some perspective on the respondents' attitudes toward the use of government services (antipathy might be expected to lead to lower rates of use), as well as their opinions of specific options, such as vouchers, insurance-type systems, etc.

The schedule concludes with a series of questions designed to assess the nature and severity of the handicap, and to gain some information about the family (size, composition, etc.). The interviewer estimates socioeconomic status ranking and parents' attitudes toward the handicap.

PRELIMINARY RESULTS

Too few interviews have been completed at this time to permit much generalization from the data, but the first third indicate some potential findings. For illustration, we discuss three types of preliminary findings.

Need for Direction

There seem to be three major access points to the service system, roughly corresponding to what seem to be three most pressing needs for service: doctors (whether private or in agency clinics); schools; and agencies providing financial assistance (such as Medicaid). From these points, clients move on to other agencies in a manner that can be better pictured as a chain than as a decision tree. Instead of surveying possibilities for supplying their needs for service and choosing the best alternative according to some explicit criterion, potential users go from one program to another, seeking referrals from each agency in the chain until they find help for their particular problem. Very few respondents had ever made any attempt to learn what services were available in order to select from among them, though some expressed a desire to do so.

One unmet need is for information, both about the child's handicap and about sources of assistance. The need for information about the handicap takes two forms—a desire for more thorough explanation from the professionals who either examine or treat the child, and a desire for counseling programs to help the parent (and sometimes the child) understand and come to terms with the handicap. The need for information about sources of assistance usually takes the form of a protest that the respondent “doesn't know what can be done or how to find out what can be done” or that they do not know where to get the help they have been told their child needs. They need “direction.” Certain patterns of service use begin to emerge. There are parents who seek only the kinds of services that someone—doctor or teacher—tells them that they need to obtain. There are also those who attempt to find out what can be done for their child, but who either cannot find out where to get the service or who fail to follow up on advice given them. Finally, there are parents who actively seek to learn something about the services available and who make persistent efforts to obtain them (with varying degrees of imagination and success).

Need for Transportation

Another unmet need of some respondents is for transportation. One Spanish-American mother who did not drive an automobile described the difficulties of taking her infant son to a clinic across town for eye surgery. Still bottle-fed, wearing eyepads, and uncomfortable from previous surgery, he was hard to manage on a crowded bus. Another feared that a lack of transportation for her partially-sighted daughter would be a problem in finding and holding a job. The family lived in an area poorly served by public transportation, and the parents' job managing an apartment complex often prevented their driving to schools, employment agencies, or social events.

Parental Goals for Children

Some definable types of parental goals for their handicapped children have emerged. The most ambitious is the wish to help the child “live up to his fullest potential”—not merely his potential as a handicapped person, but as a human being. In this view, the handicap is an obstacle to be overcome—not an insurmountable problem. One mother of a 19-year-old high school senior with very little residual

vision remarked that he was able to "make up in intelligence what he lacked in vision." The boy intended to become a scientist and was trying to choose between Berkeley, Caltech, and the Northrop Institute of Technology.

A second parental goal expressed in the interviews is to help the child "be as much like normal children as possible." Normality is seen as the upper bound of the child's possibilities. One mother of two deaf boys had made a particularly thorough attempt to compare her boys to normal children and to duplicate for them all the experiences of the others. She bought them hearing aids and Vibra-alarm clocks to increase their sensory independence; she encouraged them to have paper routes and other money-making projects; a physical education teacher herself, she enrolled them in an ice-hockey league and helped them engage in other sporting activities. She was eager to have them transferred from a special school for the hearing handicapped into regular schools, and liked the special school they attended because transfer was its goal, too.

A third type of parent seems to have more limited goals for the child. Rather than normality, the parent hopes that the child can achieve enough independence—financial and personal—to be a "functioning, if handicapped, member of society." Such parents seem to be particularly concerned with things—special education and training—which are seen as a means to the end of financial independence.

Financially, the least ambitious goal is the wish to help the child "adjust to his handicap," to come to terms with it in the sense of learning to live with it rather than overcome it. As might appear obvious, the extent of parental ambitions for the child is related to the severity of the child's handicap—less was hoped for for those who were most severely impaired. But while the severity of the handicap may be a major variable in parental attitudes, other qualities and styles of service use seem to be related to it. For example, some adjustment-oriented parents mentioned a need for counseling. "Fullest-potential" parents tended to emphasize academic education; the "normalizers" tended to want special equipment to improve their children's sensory skills.

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