

## DOCUMENT RESUME

ED 134 614

95

TM 006 022

**TITLE** Assessment of Selected Resources for Severely Handicapped Children and Youth. Volume I: A State-of-the-Art Paper.

**INSTITUTION** Abt Associates, Inc. Cambridge, Mass.

**SPONS AGENCY** Office of Education (DHEW), Washington, D.C. Office of Planning, Budgeting, and Evaluation.

**REPORT NO** AAI-74-08

**PUB DATE** May 74

**CONTRACT** OEC-0-73-7030

**NOTE** 167p.; For related documents, see TM 006 022-025

**EDRS PRICE** MF-\$0.83 HC-\$8.69 Plus Postage.

**DESCRIPTORS** Bibliographies; Costs; Deaf Blind; Emotionally Disturbed; Handicapped Children; Legislation; Measurement; Mental Retardation; Multiply Handicapped; Rehabilitation; \*Research Reviews (Publications); \*Services; \*Severely Handicapped; \*State of the Art Reviews; Youth

**ABSTRACT**

This state-of-the-art paper is one of several volumes which describe the characteristics, quality, and costs of services to severely mentally retarded, severely emotionally disturbed, deaf-blind, and severely multiply handicapped clients age 21 and under. Part I of the volume consists of a subjective distillation of the concepts and research reported in Part II. It discusses many of the issues for which documentation and research support are later provided. It also includes an historical context for the three major categories of handicap and treats some issues on which little research is available. The final section of the first part presents some of the speculations as to the direction that provision of care for the severely handicapped will be taking in the future. Part II is the research review containing five sections. The first four represent the handicapping conditions of interest to this study: severe mental retardation, severe emotional disturbance, deaf-blindness, and severe multiple handicaps. The research is discussed under the same basic rubrics wherever possible. For the three major handicap categories (mental retardation, emotional disturbance, and deaf-blindness), there are the following subsections: problems of definition and classification; prevalence studies; research and demonstration; measurement; guides to providers; and bibliographies. The treatment of the fourth category, multiple handicaps, is much shorter and has fewer subsections. The fifth and last section covers research studies which are concerned with more than one type of handicap. (RC)

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# ASSESSMENT OF SELECTED RESOURCES FOR SEVERELY HANDICAPPED CHILDREN AND YOUTH

TM006 022

Volume 1. A STATE-OF-  
THE-ART PAPER

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Abt Associates Inc. 1974

ASSESSMENT OF SELECTED RESOURCES  
FOR SEVERELY HANDICAPPED CHILDREN AND YOUTH

Volume 1: A State-of-the-Art Paper

Abt Associates Inc.  
55 Wheeler Street  
Cambridge, Massachusetts

AAI Report No. 74-08

May, 1974

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The research reported herein was performed pursuant to a contract with the Office of Education, United States Department of Health, Education and Welfare. Contractors undertaking such projects under Government sponsorship are encouraged to express freely their professional judgment in the conduct of the project. Points of view or opinions stated do not therefore necessarily represent official Office of Education position or policy.

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## PREFACE

### Project Overview

July, 1973 Ant Associates was awarded a contract by the Office of Planning, Budgeting and Evaluation (OPBE) of the United States Office of Education to conduct a nationwide "Assessment of Selected Resources for Severely Handicapped Children and Youth" (Contract No. OEC-0-73-7030). The present volume is one of a five-volume series produced over the course of the project to describe the characteristics, quality and costs of services to severely mentally retarded, severely emotionally disturbed, deaf-blind and severely multiply handicapped clients age 21 and under, in 100 providers across the nation.

For the purposes of this study, "severely" handicapped children and youth were functionally defined as those persons age 21 and under who are either mentally retarded, emotionally disturbed, deaf-blind or multiply handicapped and who exhibit two or more of the following behaviors with a high degree of regularity:

- Self-mutilation behaviors such as head banging, body scratching, hair pulling, etc. which may result in danger to oneself;
- Ritualistic behaviors such as rocking, pacing, autistic-like behaviors, etc. which do not involve danger to oneself;
- Hyperactive-aggressive behaviors which are dangerous to others;
- Self-stimulation behaviors such as masturbation, stroking, patting, etc. for a total of more than one hour of a waking day;
- Failure to attend to even the most pronounced social stimuli, including failure to respond to invitations from peers or adults, or loss of contact with reality;
- Lack of self-care skills such as toilet training, self-feeding, self-dressing and grooming, etc.;
- Lack of verbal communication skills;
- Lack of physical mobility including confinement to bed, inability to find one's way around the institution or facility, etc.

The project was conducted in three phases: I) review of the literature and development of a state-of-the-art paper and annotated bibliography; II) conduct of a survey of potential providers of services to severely handicapped clients age 21 and under and the development of data collection instruments for use in the third phase; III) site visits to 100 providers, data analysis and report writing.

Phase I consisted of an extensive review of the literature for the purpose of developing an annotated bibliography and state-of-the-art paper on research and services for severely handicapped children and youth. Volumes 1 and 2 of the series were developed during this phase of the study.

Phase II included the development of data collection instruments for use during the third phase and a mail survey of potential providers of services to severely handicapped children and youth across the nation. The survey was conducted for the purpose of creating a pool of providers from which 100 facilities could be selected for site visits. From the 1,550 respondents to the mail survey, 100 providers were selected who serve severely handicapped clients age 21 and under. The selection of the 100 providers was accomplished by grouping the respondents to the survey into eight sampling categories according to whether they offered primarily day or residential services and according to the number of severely handicapped clients age 21 and under they served. In order to obtain a final sample of providers which served a range of handicapping conditions, providers were also selected based upon whether they served a majority of clients who are either severely mentally retarded, severely emotionally disturbed, deaf-blind, or severely multiply handicapped. In addition, some providers were selected who served a mixed severely handicapped population.

Phase III of the study consisted of data collection, analysis and report writing. Each of the 100 providers in the final sample were visited by two Abt Associates field staff for approximately two days during May or June, 1974. During these visits the Abt field staff conducted interviews with the program or institution director, selected ward, unit or classroom staff who were most knowledgeable about the services being offered to

severely handicapped clients; and the budget director or other personnel most knowledgeable about the provider's budget and costs of services. In addition, one member of the field team spent one of the two days observing severely handicapped clients throughout the facility. These data were analyzed by Abt Associates project staff and descriptive case studies were written to provide a composite picture of the characteristics, quality, and costs of provider services to severely handicapped clients.

The output of the study consists of a five-volume final report as follows:

- Volume 1: A State-of-the-Art Paper
- Volume 2: A Selected, Annotated Bibliography
- Volume 3: Data Analysis and Results
- Volume 4: Case Studies of Provider Services
- Volume 5: Conclusions and Recommendations

### ACKNOWLEDGMENTS

The conceptualization and development of Volume 1: A State-of-the-Art Paper was undertaken in Phase I of the project, during which Dr. Carolyn Stern was Project Director for the study. Dr. Stern was responsible for the tremendous effort involved in directing a major literature review and for synthesizing the material into the present paper. It is to Dr. Stern that the major credit for authorship of this volume belongs.

Dr. Stern was assisted in the initial drafting of the state-of-the-art paper by a number of Abt Associates staff whose work deserves recognition. Elizabeth Boyle, Ruth Freedman, Laura Studen and Donna Warner deserve special thanks for their efforts in conducting the literature search and for drafting sections of the original report. To Deborah MacKiernan, contract secretary during this phase, goes a round of applause for the efficient production of successive approximations of the volume.

We are especially grateful to Elizabeth Rasmussen, our OPBE Project Officer, for her invaluable direction and assistance in ensuring that the report would meet the needs of federal decision-makers concerned with the development of policy relating to services for severely handicapped children and youth. For her commitment to the study and her continued enthusiasm and support we are deeply indebted.

In addition, we would like to thank Paul Thompson of the Bureau of Education for the Handicapped and Nelson Ford of the Office of the Assistant Secretary of Planning and Evaluation for their timely comments on the draft report.

Patricia Cook, Project Director  
Elinor Sorensen, Deputy Project Director

May, 1974

## FOREWORD

Over the long course of man's history, it has been only comparatively recently that atypical children, those with physical, mental, or emotional anomalies, were considered worthy of public concern. Until the middle of the nineteenth century, the Poor Laws, inadequate at best but more frequently ignored than implemented, were the only public recourse for the care of handicapped children. Because the frequency of epidemics at the public almshouses consisted a health hazard, and the presence of criminals and depraved adults was considered to be morally corrupting, such children received what might be euphemistically called "residential care" only until they could be apprenticed out or indentured. Factory owners who wanted the labor of the able-bodied poor children were forced to take a number of crippled or handicapped children as well. Since no records were kept and the contractor was not held accountable for the children entrusted to him, the fate of the handicapped child can be easily imagined.

Even while the prevalent mode was auctioning or indenturing of unwanted children, the early years of the nineteenth century saw a gradual differentiation among the various types of handicaps. On the continent, the separation of the mentally retarded child from psychotics was conceptually recognized long before separate arrangements for care were provided. In France, Seguin began developing physiological and sense training methods for the education of mentally retarded children in 1839, and the first school for the feeble-minded in the United States was opened in Massachusetts in 1848. Although legislation for the establishment of a similar institution in New York had been introduced two years earlier, no action was taken there until 1851.

About this same time, there was a growing concern for the care of children with other types of handicaps. By 1850 there were eight state institutions for the blind and by 1860 there were six states with some provision for emotionally disturbed children. Even before the movement to educate the mentally retarded children had gotten off the ground, however, the sociological studies of the Jukes and the Kallikaks ushered in a period in which feeble-mindedness was associated with crime, pauperism,

and degeneracy. Since such experts as Tredgold in England and Goddard in the United States had stated categorically that at least 90% of the etiology of mental retardation was hereditary and Seguin's work had not produced the dramatic "cures" anticipated, the budding interest in education was shifted to the ultimate solution, sterilization.

Even the great Fernald, after whom many schools for mentally retarded people have been named, had little constructive to say about the mentally retarded. In a speech given in 1912 he stated:

The feeble-minded are a parasitic, predatory class, never capable of self-support or of managing their own affairs. A great majority ultimately become public charges in some form. They cause unutterable sorrow at home and are a menace and danger to the community.

- o Feeble-minded women are almost invariably immoral... the high grade imbecile is a potential criminal needing only the proper environment and opportunity for the development and expression of his criminal tendencies.

The converse proposition, that "the proper environment and opportunity" could also make it possible for these human beings to lead fulfilled and socially useful lives, was not explored.

Subsequent to World War I and continuing along into the 1950's, a great deal of attention was given to developing theoretical formulations concerning handicapping conditions. Public provision for handicapped children and adults continued to expand during this period, but the primary function of such institutions was segregation. Facilities continued to be basically warehouses for the storage of bodies, where those who were unpleasant or offensive because they were unproductive, incompetent, and/or unable to control their bodily functions, were provided with minimal subsistence until a "natural" death occurred. With some slight amelioration, these were the conditions which generally prevailed until after the election of President John Kennedy.

In his Message to Congress in February, 1963, President Kennedy indicated his intention to develop a "bold new approach" to the care of the mentally handicapped so as to maximize their possibilities of assuming a useful role in society. This period was also influenced by the pre-

occupation with the effects of cultural deprivation, environmental handicaps, and the unequal opportunities afforded minority people, which were having such an important impact at that time.

During the decade which has elapsed since then there has been an enormous investment of public funds in studying the etiology of handicapping conditions and in the development of treatments and techniques for ameliorating their effects, with the result that a voluminous literature is now available. One of the major changes in emphasis in this period has been from primarily basic care to habilitative or rehabilitative services. Only recently has legislation been passed in some states assuring every child, no matter how severely handicapped; an equal opportunity to receive as complete an education as possible. A corollary of this recognition of public responsibility is the belief that even the most severely handicapped person has the right to, and is capable of, a meaningful life.

In spite of numerous studies, demonstrations, and outright grants to providers, the Bureau of Education for the Handicapped estimated in 1973 that only 40% of approximately 7,000,000 handicapped children were receiving adequate services. Furthermore, since the incidence of severity along the dimension of handicap has not been charted, it is extremely likely that a large proportion of the unserved fall into the category of the severely handicapped. There is thus a critical need to survey the literature and determine what is known about this disproportionately neglected segment of the handicapped population. The present work is an attempt to respond to this need.

#### RATIONALE AND ORGANIZATION OF THE STATE-OF-THE-ART PAPER

In preparation for the writing of this paper an extensive literature review was conducted, resulting in the volume entitled: "A Selected, Annotated Bibliography on Severely Handicapped Children and Youth." Most of the articles, books, and other sources mentioned in this paper are fully referenced in the Annotated Bibliography.

The State-of-the-Art paper actually comprises two distinct parts. Part I consists of a subjective distillation of the concepts and research reported in Part II. It discusses many of the issues for which documentation

and research support are later provided. In addition, it includes an historical context for the three major categories of handicap and treats some issues on which little research is available. The final section of Part I presents some of the speculations as to the direction that provision of care for the severely handicapped will be taking in the not too distant future.

Part II of this report is the research review. There are five sections. The first four represent the handicapping conditions of interest to this study: severe mental retardation, severe emotional disturbance, deaf-blindness, and severe multiple handicaps. In every case the focus is on those children and youth with the most severe levels of impairment.

In each of the above four categories, the research is discussed under the same basic rubrics wherever possible. For the three major handicap categories (mental retardation, emotional disturbance and deaf-blindness), there are the following subsections: Problems of Definition and Classification; Prevalence Studies; Research and Demonstration; Measurement; Guides to Providers; and Bibliographies.

The treatment of the fourth category, multiple handicaps, is much shorter and has fewer subsections. This is due only in part to the fact that there is comparatively little literature in this area. More importantly, the category itself is extremely amorphous. There is always the need to strip away the global characterization of "multiple" and look at the specific physical anomalies and performance disabilities of which it is comprised. For this review, all references in which one of the handicaps of concern is either deafness or blindness, or both, are discussed under the Deaf-Blind rubric (section 3.0); the multiply handicapped mentally retarded are included in the section on Mental Retardation (section 1.0) and the emotionally disturbed mentally retarded are under Emotional Disturbance (section 2.0).

Yet the designation of multi-handicapped has acquired a uniqueness and identity of its own in the past few years. This is probably due to the fact that the rubella virus, which has such a devastating effect on the embryo during its developmental course, after the epidemic of 1964-65 resulted in the birth of a great many children handicapped in perceptual, sensory-motor, and mental functioning. Thus the multi-handicapped category comprises

a combination of sensory, mental, and physical problems, and includes brain-damaged, cerebral palsied, and orthopedically impaired children as well.

The fifth and last section covers research studies which are concerned with more than one type of handicap; they could reasonably have been cited in two or more of the four preceding sections. This alternative would have resulted in a great deal of redundancy, and would also have risked losing some of the total impact of the original documents. It was therefore rejected. Instead, a fifth section entitled, "Research on All Severe Handicaps," was created. In it are reviews of a number of textbooks and compilations of materials. Most importantly, it includes the Guides to Providers serving the entire range of handicapping conditions. It does not, however, have the usual subsection on Research and Demonstration since few such studies focus on more than one handicapping condition. In addition, the final section includes material on current legislation as well as costs of services to severely handicapped children and youth across all four handicapping conditions.

## PART I: SEVERE HANDICAPPING CONDITIONS

After a thorough immersion in the literature, we have become aware of several dominant themes which surface again and again. By far the most persistent of these is the realization that it is both futile and non-productive to attempt to separate the problems of definition and classification from those of measurement and estimates of prevalence. Two major themes derive from this position. The first is the need to cut free from the traditional categorical labels, to deal with persons, not diseases and deficits. Once this leap has been taken, a number of corollary issues emerge, relating to treatment approaches and settings.

The second major theme is less perceptible and has a much more difficult time breaking through the impacted theories of various disciplines. It postulates a need to address the problems of the severely handicapped on three separate levels: prevention, remediation, and education.

These pervasive themes will be discussed in detail in the subsequent sections of this paper. However, before we can fully understand the bases and rationale of the categorical approach, we need to examine briefly the historical roots which have nourished the growth of theory and knowledge in the three major handicap areas.

### 1.0 HISTORY OF THE CATEGORICAL APPROACH

#### 1.1 Mental Retardation

The history of our knowledge of mental deviations extends far back into the pre-Christian era. The Therapeutic Papyrus of Thebes (1552 B.C.) contains undoubtedly the oldest written reference to mental retardation. Too, Galen, a Greek physician in the second century A.D., discussed variations in mental ability in his medical writings, and there were many other early philosophers and scientists who were interested in exploring the most extreme forms of human behavior.

Among primitive and superstitious peoples, "fools" were thought to be "touched" by God, and were accordingly given many privileges and considerations not enjoyed by normal members of society. Or conversely, they were considered "possessed" by the devil and persecuted as witches. At other

times, a deviant child was considered God's curse for the misdeeds of the parents, and hence a shameful stigma. In any case, abnormality was commonly viewed as an unfortunate accident, a "sport" quite unrelated to the hereditary patterns of the parents or their living conditions.

Thus, the Greeks were known to have killed or abandoned handicapped children. The Romans could afford the luxury of maintaining a certain number of the more amusing variety as "fools" for their entertainment, while the Persian religion demanded compassion and care for unfortunates. Similarly, the Christian dogma which prevailed during the Middle Ages preached man's responsibility for all his human brethren, including the sick, the poor, and the handicapped. Many deaf, blind, and mental incompetents were offered havens in hospitals and asylums of various religious orders. A famous religious shrine at Gheel placed both the insane and feeble-minded in private homes; these were probably the first formal "family-care" arrangements. About the same period, in England, the mentally incompetent were supported as wards of the king. Ironically, with the period of the enlightenment and the concept of individual responsibility, a far less liberal attitude was displayed to those who not only could not make a productive contribution to the economy, but were also a drain on its limited resources.

In all this early history, it should be pointed out, there was no real effort to categorize the varieties of incompetencies. Rather, there was what might even be considered a behavioral approach. Persons who were abnormal and did not "fit in," for whatever reason, were commonly dealt with in the same way. We find the "poor, halt, and blind" in the same almshouses and dungeons, while the manic and potentially dangerous deranged or defective persons were often placed in prisons, even though they had not committed any crimes.

A definition of severe mental retardation couched in modern terms first appeared in 1534, and a distinction was made between idiocy and insanity in 1690 (Doll, 1972). From these beginnings, the trend toward categorical labelling began in earnest. For years, work with the retarded continued to be tied closely to the sensory methods developed in the study of the deaf and the blind. Thus, almost all of the early progress in education and rehabilitation was made by physicians rather than educators. And so there

is a logical basis for the medical-pathological orientation which continues to permeate a great deal of the research and treatment of the handicapped. As medical research and practice branched out into numerous areas of specialization, a corresponding effect was felt in the study of all types of abnormal manifestations. The new sciences such as genetics, pathology, neurology, biochemistry, etc., each cut off a small segment of the total problem to examine microscopically and separately, coming together only to add still another term to the burgeoning list of etiological descriptions. These were considerably augmented, at the turn of the century, with the emergence of the social sciences. Now psychology, psychiatry, sociology, anthropology, and all their splinter disciplines, produced a new source of categorical classifications.

### 1.2 Emotional Disturbance

The early study of behavioral disorders did not become dissociated from that of mental deviance in general until the beginning of the 18th century.

However, although references to behaviors which now would be categorized as severe emotional disturbance appeared in the medical and psychiatric writings of the 1800's, the deviancies were described in the terminology appropriate to adult psychoses. This homunculus approach led to the diagnosis of infantile manias or infantile insanity. Most of the time, however, children with behavioral disorders were considered under the rather amorphously defined rubric of mental deficiency, with or without organic deterioration.

Perhaps the first labels applicable to children and youth were coined by Kraepelin in his text, Dementia Praecox, published in English in 1919. This broad complex of syndromes was used retrospectively to identify adults whose aberrancies had their roots in early adolescence, or even, in a small percentage of cases, early childhood. One of these, hebephrenia, soon began to be used in diagnoses with adolescent patients. Kraepelin believed that the various forms of dementia praecox were due to cerebral degeneration or metabolic disorders which were both progressive and irreversible, providing a completely pessimistic prognosis. In effect, this important

contribution to the analysis of adult psychoses discouraged research on the disorders of young children.

The attribution of psychoses to physiological causes continued to be dominant in psychiatry for a long time after Freud had brought out his theories of the psychological and emotional genesis of abnormal behavior. Not until Bleuler formulated his concept of the "schizophrenias" was there any published record of an attempt to coordinate physiological and psychological theories. Although applied primarily to his work with adults, Bleuler's description of the major symptoms of schizophrenia converts readily and usefully to the classification of disorders in children. It also provides the basis for the therapeutic-analytic orientation which has until recently been the prevalent method for dealing with behavior disorders of young children. Most psychiatrists continued to view the appearance of deviant behaviors in children simply as the forerunner of adult psychoses. A major basis for the unwillingness to designate any behavior in young children as abnormal was the absence of guidelines for the description of normal development. This was particularly true where the principle of continuity of human behavior was accepted. Under this formulation, all behavior is continuous and there are no sharp points of distinction between the normal and the abnormal; there are only degrees of variation from a hypothetical norm. Discontinuity theory postulates that aberrant behavior is not only a difference in degree or quantity of unusual behaviors exhibited, but also a major difference in the kind or quality of these behaviors. The conflict between continuity and discontinuity theories continues to be a major area of disagreement at the present time.

With the advent of the 1930's, the consideration of behavior disorders in children began to take on an identification apart from work with adults (e.g. Potter, Bradley, Despert, Mahler, Szurek, Bender, Kanner). Although described in different terms by the early investigators, there seems to be consensus on certain characteristics of the emotionally disturbed child. These include lack of contact with reality, inability to form emotional relationships, defects of verbal communication and sensory reception, and bizarre psychomotor behavior. Emotional disturbance has been described as a generic societal problem which involves three major characteristics:

disability, deviation, and alienation. Yet it is more than a simple sum of its varied manifestations: it is a human system in distress.

Because current work with emotionally disturbed children has so many different theoretical sources, there have been a number of attempts to develop a conceptual framework which retains all the variety without losing any of the power of analysis and interpretation.

A number of theoretical models have been constructed to deal with pathological behavior. Each of these encompasses a basic methodology, a distinctive orientation, some integrative principle related to behavior genesis, an approach to amelioration, and a unique stamp or ambience which distinguishes it from other models. There are three general theoretical models: psychotherapeutic, behavioral, and sociological. In addition, several less complete models derive from the basic three. The psychotherapeutic model has clear ties to Freudian theory, with many modifications and new insights introduced into the system over the intervening 70 years. The behavioral-psychological approach can ultimately be traced to the traditional conditioning theories of Pavlov, although these were completely transformed by Skinner in his development of operant psychology. Finally, Durkheim is generally credited with the application of sociological theory to the etiology and interpretation of deviant behavior. The several theoretical systems may emphasize different features of specific syndromes. Psychotherapy, behavioral psychology, and biogenetic theory, for example, relate to the manifestation of the disability; sociology is concerned primarily with deviation.

The various theoretical positions are further confounded by the contributions of a rather distinct group of critics who oppose all theoretical models of aberrant behavior. For convenience, they have been labelled the "counter-theorists." Deriving from the existential philosophy of Husserl and Heidegger, they are unified by their radical challenge to the accepted preconceptions of disturbance, deviance, and psychosocial disability. They are not a homogeneous group. Herbert Marcuse and Norman Brown are socio-cultural reformers who tend to a behavioral model, while Laing has come out of the traditional psychodynamic school. They share a common rejection of current methodology, they refuse to reduce ideas to prescriptive principles

of behavior genesis, and they object to current treatment methodologies. On the positive side, they believe that all human behaviors should be freed of repressive institutionalization and cultural imposition, and they maintain that, even the most bizarre behaviors are still part of the total spectrum of possible human responses.

Counter theory has had a considerable impact not only on the description of emotional behavior but also on the entire categorical approach. This has been accomplished in spite of the fact that counter theorists have produced no crucial evidence nor critical experiments to invalidate any of the basic principles of behavior on which the major theories are built. The usefulness and applicability of basic paradigms of learning theory, unconscious motivation, and biogenetic and sociocultural determinants, have not been seriously threatened. However, what counter theory criticism has done is to point up the necessity of integrating the three theoretical systems into a unified model of behavioral analysis and treatment.

### 1.3 Deaf-Blind and Multiply Handicapped

Next to mental retardation, deafness and blindness, as separate sensory disabilities, have the longest historical background of any of the handicapping conditions. However, there are surprisingly few references to the deaf-blind as a single entity. Perhaps the most important contributions to the field have been made by dramatic successes achieved by persons such as Helen Keller and Laura Bridgman. These and a few other instances led to the recognition that special techniques could be used to break through the communication barrier so that the deaf-blind could eventually be educated.

There have been many conflicts as to the value of various instructional approaches. Some time ago, it was established that there was no physical basis for muteness in the deaf-blind. This led to a strong push to teach the deaf-blind to speak through the use of various vibratory and acoustical techniques. The distorted sounds which were produced after a tremendous expenditure of effort were a deep disappointment. Today there is a turning away from the focus on mechanical production of sound to an emphasis on increasing conceptual power through whatever sensory input channels are available.

There have also been some areas of disagreement as to what level of measurable sensory deficit is to be used as the legal definition of blindness or deafness. Yet at no time has there been any serious disagreement as to whether or not a person is severely handicapped as a consequence of a combination of these two deficits. Furthermore, since deafness and blindness are tied to identifiable physical structures involving peripheral and central nervous system networks, there has been little basis for conflicting causal attributions. The reasons why the physical impairment occurred may be questioned, but not (except in cases of hysterically simulated sensory impairment) the association of physical anomalies with deficits in function.

The historical background of the multiply-handicapped category is also very limited. It, too, has been torn by conflict between different theoretical systems, but for opposite reasons. The whole category of multiple handicaps is so amorphous that it may be considered a tacit admission of the breakdown of efforts at classification. Thus, it has contributed to the growing dissatisfaction with labeling and categorical classification.

## 2.0 PROBLEMS OF DEFINITION AND CLASSIFICATION AS THEY RELATE TO MEASUREMENT AND PREVALENCE STUDIES

Whenever prevalence studies or incidence estimates have been reported, there has been some cautionary note as to the questionable validity of the data. Attempts to obtain definitive estimates of "the handicapped" will continue to prove fruitless until the rules of the census game are made sufficiently clear so that one person cannot be assigned to two or three different pigeon holes at the same time. Too, they must be sufficiently objective so that two census-takers do not attach different labels to the same person. Such considerations quickly bring us to the problem of classification and measurement.

Even if these problems did not exist, there is one very serious hurdle to the prevalence survey which does not seem to have been addressed in the literature. This concerns the sources from which data are obtained. In most cases, incidence surveys canvass a variety of institutions: regular schools, special classes, clinics, hospitals, etc. Using the traditional categorical labels, they ask teachers or administrators to report how many

children in their class or program are in each of the categories. There is no basis for assuming that teachers are capable of making such fine-grained diagnostic determinations. Even if they were, there is a problem which even expert diagnosticians must face: under what label does one count an untestable deaf-blind child with emotional disorders? The situation is further complicated by the fact that many surveys are themselves categorical in nature. Survey A is interested in the deaf-blind; Survey B in the mentally retarded; Survey C in the emotionally disturbed. Thus, a child in the Multi-Handicapped Unit of a School for the Deaf could legitimately be counted three times. And a fourth time, if there were a survey of the multi-handicapped.

In contrast to these sources of overestimate, there are other conditions which produce underestimations of the "true" incidence statistics. The prevalence estimates of the severely emotionally disturbed reported by one investigator is 4 in 10,000. This figure was obtained from a survey of classroom teachers. Again, accepting the unwarranted assumption that a classroom teacher has the expertise to make such a diagnosis, any inference that this figure represents the incidence of severe behavior disorders is preposterous. There is no reason to believe that even one-quarter of severely handicapped children in the United States are presently enrolled in public school classes.

So, how does one go about taking a census of handicapped persons? A number of prevalence studies have indicated that 40% to 60% of school-aged handicapped children are not receiving any type of care at all. It is unclear how these figures were determined. Most likely they were derived from the application of statistical properties of the normal curve to the total population. While this may be a valid procedure where characteristics are normally distributed, it is certainly not appropriate where the conditions by their very nature are abnormally distributed.

There is strong evidence that extreme behavioral or physical anomalies are accidents of nature or environmental circumstance. For example, it has been estimated that approximately 90% of all those with an IQ score between 52 and 67, i.e., the "mildly" retarded, have no measurable brain damage or central nervous system impairment. Because of the need to find an etio-

logical label, they are called "cultural-familial" retarded children. They are simply assumed to be at the lower end of a normally distributed attribute, intelligence.

The picture changes radically when we get to the severely and profoundly mentally retarded. Almost all persons in this category show evidence of accidental and unpredictable genetic mishaps, viral infections, birth injuries, etc. The occurrence of biological "sports" is not associated with ethnicity, socioeconomic status, or any of the other heritable variables to which mild retardation is linked. It is unsafe to apply population estimates to determine the actual size of a severely handicapped group.

A census of the handicapped must, therefore, be a true census--that is, an actual door-to-door head count. This task would be a difficult one, even assuming that the money for such an expensive venture were made available. In the first place, many of this group never surface to where they can be counted. Many families fail to report children of whom they have divested themselves by permanent placement in a residential institution, or those they have locked up in a back bedroom or closet. The feelings of guilt and shame engendered by such offspring do not permit their acknowledgement, even to an impersonal census-taker. But suppose this were not true, and the parent were willing to admit to a handicapped child in the family; would a lay person be able to determine whether a mute, unresponsive child was deaf, profoundly retarded, or autistic? Even specialists often disagree as to the appropriate label to apply to a particular syndrome of atypical behaviors.

Thus we return to the problem of specifying the rules of definition and measurement by which the game of classification must be played. Borderline discriminations, where behaviors are only moderately deviant from normal, are admittedly far more complex. There are so many confounding environmental variables--socioeconomic, ethnic, cultural, and social--which may prevent the emergence of inherent abilities, or precipitate the appearance of sensory or behavior disorders. In comparison it is a far simpler task to identify a severely handicapped person, for the severity makes the deviance obvious. Here the problem is one of identification, description, and measurement.

As we have seen, the problems of definition and classification are rooted in the separate historical processes through which each area of handicap has created its own body of theory and terminology. Even today, there are "specialists" in mental retardation, behavior disorders, the deaf, and the blind; and there are a host of "specializations" covering brain damage, cerebral palsy, and many other physical and orthopedic disabilities.

The press for greater specificity of classification has recently been given renewed impetus by the need of legislators concerned with enacting laws to protect the rights of handicapped populations. Since these laws adopt the traditional categorical terminology, with special provisions for different types of handicapping conditions, clear guidelines for discriminating the different populations become essential.

Compilations of state laws dealing with the handicapped point up the stereotypic language. The following definition, although better than most, is a fairly typical example: The exceptional child is "any child of educable and trainable mind, under 21, for whose particular educational needs institutional care and training are not available in this state, or who cannot pursue regular classwork due to reason or reasons of defective hearing, vision, speech, or mental retardation, or physical condition as determined by competent medical authorities and psychologists." This description provides no real basis for identifying the handicapped child, and places the entire onus of this responsibility on some ill-defined group of authorities.

In certain states there are legal stipulations which decree that children with IQ's below 90 cannot be considered emotionally disturbed. Accordingly, Residential Treatment Centers for the emotionally disturbed specifically exclude the mentally retarded. How then can they determine whether or not the mute, out-of-contact child is capable of normal mental functioning? Most schools for the deaf and blind will not accept the retarded, even though they may also be deaf and/or blind. Who can say to what degree failure to perform on an IQ test is a function of impaired mental ability, or the closed channels of sensory stimulation which it is the task of these institutions to open? There must be some objective basis for determining at what point mentally retarded or emotionally disturbed children can no

longer be retained in regular classrooms. If they are excluded, who decides whether a special class or a residential facility is most appropriate, and on what basis?

The question of establishing levels of severity of impairment is another aspect of the problem of classification. There is a growing tendency to base the determination of levels of severity on behavioral criteria, regardless of the medical or etiological diagnosis. The presentation of two or more critical negative behaviors, such as self-mutilation or bizarre posturing, and/or the absence of two or more developmentally-appropriate positive behaviors, such as responsiveness to social stimuli in the infant or basic self-care skills in the preschooler, are obvious and indisputable evidence of a serious degree of departure from normal expectations.

### 3.0 THE NON-CATEGORICAL ARGUMENT

It is but a short step from the adoption of behavioral criteria for specifying level of severity to a complete rejection of all categorical labeling. There is no real justification for establishing categorical boxes and then stuffing into them persons who have their own unique sets of characteristics. It is far more reasonable to observe the handicapped person to determine the undesirable behaviors which need to be extinguished and the desirable skills and abilities which need to be acquired. Then a treatment course can be charted specifically for this particular person.

This, in essence, is the non-categorical stance. Basically, it is but an extension of the principle of individualized instruction to the handicapped child. There are two roots from which the concept of a non-categorical approach has grown: the first relates to the rejection of labels, per se; the second, to the need for alternative educational settings. There is a strong feeling that it is unethical and immoral to label a child as different or deviant from his peers. Aside from being dehumanizing, once the stigmatizing label has been applied it serves as a deterrent to any attempt to deal with the specific problems of a particular child. In the not-too-distant past, children who had been labeled in this way were placed in institutions for the severely retarded, with others similarly categorized, where

they were almost completely deprived of any educational stimulation. The horror stories which occasionally seeped out of these institutions led to reform pressure by parental and citizen groups, which precipitated the establishment of the "special" class within the regular school building. It is a moot point whether these "special" classes can be considered an improvement. There is no evidence that special classes facilitate either cognitive or social development. On the contrary, there is some reason to believe that placement in a special class exposes the child to greater emotional stress, ridicule, and opprobrium. Although there is a smaller child-teacher ratio, all children are treated alike, as if the homogeneous label had stripped them of all individuality.

Disappointment and dissatisfaction with the special class resulted in a swing to the opposite extreme--the demand that all children should be retained in the "mainstream" of the educational system. Children would be classified in terms of their behavioral and learning disabilities, for which they would receive appropriate instruction, but they would also participate in many of the class activities. This system seems to be working out with certain types of handicaps, and with rather moderate levels of severity. Teachers need some retraining, and they welcome the assistance of support staff. In general, they are pleased and surprised at the progress of the handicapped children.

Children with severe handicaps continue to need special class placement, but with an entirely different orientation. A new approach provides far greater flexibility of programming and much more supervised contact with other children. Such a program is functioning successfully within a complex of three regular schools in a California community. In the classes are many rubella children who are deaf and blind; some are also mentally retarded and emotionally disturbed. Several severely disturbed boys are also accommodated in this non-residential program. There is no doubt that the non-categorical approach can and does work (Meyen, 1971; Reynolds and Davis, 1971; Johnston, 1972; Sodhi, 1972).

Comparisons between public and private facilities as well as between various types of home and residential placements are frequently debated. Although the recent trend is away from large institutions to smaller units,

preferably some type of family-home care, the latter is not necessarily a superior placement. There are many advantages of institutional placement, not the least of which is the access to a greater variety of special therapeutic care and equipment. While most advocates of a non-categorical approach are opposed to the institution, it is not the institutional or residential setting which is the major point of objection. It is the principle of exclusion which is at issue.

Consider the case of the Regional Treatment Centers for Emotionally Disturbed Children, under the aegis of the National Institutes of Mental Health, and the Regional Deaf-Blind Centers sponsored by the Bureau of Education for the Handicapped. Neither of these will accept children who bear the label legally (and arbitrarily) assigned to the other. And neither will willingly accept the mentally retarded, even though the appropriate categorical deficit is also present. Aside from the dearth of diagnostic measures to establish which is the most valid label, the handicapped child is subjected to another type of injustice. Although both networks are national in scope, they are not distributed geographically in any equitable pattern. Thus, a child with emotional disturbance may have to be transported hundreds of miles to a Regional Training Center, while a Deaf-Blind Center may be located close to where he lives.

Again, we must return to a behavioral position: The best placement for any handicapped person is the one which provides the best service--the one most responsive to the totality of his or her particular needs.

#### 4.0 TREATMENT AND RESEARCH ISSUES

The majority of the research and demonstration studies are concerned with the exploration of the effects of different treatment approaches. Most of these investigations are demonstrations in which the use of a particular curriculum or instructional procedure is reported. In some cases there are pre- and post-tests to measure progress across the period of the innovation. Far more frequently, there is no objective evaluation, and no attempt to carry out even a quasi-experimental design.

The comparatively few experimental studies are equally lacking in rigor. These criticisms are particularly applicable to demonstrations of

psychotherapeutic treatment programs. There are two aspects to the problem: First, the psychotherapeutic process is extremely idiosyncratic and difficult to describe in precise, replicable terms. Much of the effect of the treatment is dependent on the charismatic rapport which is established within an analyst-patient dyad. The second aspect of the problem is in determining the success of the "treatment." Generally, studies in which groups of patients have received therapy report a recovery rate of 25%. But the criteria of recovery are extremely subjective.

The problems become even more complex if the study involves the comparison of one psychotherapeutic approach with another--for example, individual therapy with group therapy. Or one group which receives psychodynamic treatment may be compared with one which receives a behavior modification program, or with a control group receiving no treatment at all. Here we are confronted with the sampling issue. The relative severity of the condition before treatment was initiated is a critical variable in the prediction of a successful outcome. Thus, children who have language facility and those with a higher IQ have a far greater chance of making a measurable improvement.

In all handicap conditions, the IQ is one of the best indicators of functioning, whether in personal self-care skills, or in social-emotional or cognitive areas. As we have indicated earlier, severely and profoundly retarded children, i.e. those with IQ's below 35, are far more likely to have organic brain damage, with evidence of neurological impairment. These children show little progress in residential or day treatment settings. Children who present similar symptoms, but without any organic trauma, are far more apt to show improvement, even in a residential setting. There are also differences in children from homes which vary on socioeconomic, ethnic, and family variables. Thus, the characteristics of the individuals who make up the groups being contrasted are extremely critical.

Another criticism of the research with the severely handicapped is that the number of cases is usually so small that no statistical tests for significance of differences, analyses of variance, or linear regressions can be made to determine the critical variables. It is almost impossible to find appropriate controls who are not receiving some type of treatment, or who do not become involved in a treatment program during the course of

the experimental study. (It would be heartless to insist that a handicapped, disturbed child remain without treatment merely to fulfill the requirements of experimental rigor.)

While these are all valid criticisms from the point of view of a traditional experimental orientation, they are completely inappropriate in the investigation of treatment issues with the severely handicapped population. By very definition, there are very few persons who fall into this category. Where they are brought together in groups in institutional settings, it is not because they are truly homogeneous, but rather for administrative convenience. Two emotionally disturbed 10-year-olds are more different from each other than are two normal fifth-grade children. One emotionally disturbed youngster may be mute and spend hours in the same bizarre, stereotypic behavior; another may be hyperkinetic and destructive. In addition to these serious impediments to maintaining an experimental design, there are all the usual problems which plague researchers who attempt to investigate issues in naturalistic settings.

However, in spite of the methodological problems, there is sufficient evidence, from numerous replications over many years, to conclude that there is very poor prognosis for improvement under a psychotherapeutic approach. The research results, such as they are, indicate that the most severely damaged children, either mentally retarded or emotionally disturbed, show little real or persistent progress toward normal behaviors. Even with the brightest and least disturbed children, the course of therapy is long and painstaking, and the outcome dubious.

There are a number of other treatment approaches which have been tried with severely handicapped children, with more or less success. Art, music, and movement therapy have sometimes shown some impact, but they are most effective when they are instituted as part of a controlled, total environment program.

The one treatment approach which has shown consistent and repeated effectiveness with the most severe levels of several handicapping conditions is that of operant conditioning or behavior modification. The reinforcement model has been applied most advantageously in connection with precision teaching techniques and programmed instruction. Best results are obtained

when the token economy becomes an integral part of the total environment (Bijou, 1971; Pedrini and Pedrini, 1972; Jordan and Robbins, 1972; Walker et al., 1972). In a residential setting, the principles are applied in every encounter the child has either with staff or other children. In settings where the child goes home weekends, behavior monitoring continues on the bus and check-off sheets are kept during the stay at home. Parents and family members, and others in the home, are important participants in the training process; even more so when the child is in a non-residential setting.

Although operant conditioning has demonstrated its usefulness in the affective areas of emotional and social development, its dramatic success with the teaching of self-care and academic skills has been its most outstanding accomplishment. This has, on occasion, resulted in the anomalous situation where behavior modification procedures are used in the classroom while the individual child has a daily session with a psychotherapist. (One tragi-comedic incident has been reported in which a child was being punished for emitting certain verbal behaviors in the classroom and encouraged to engage in these behaviors as cathartic release in the sessions with the therapist!)

Evaluation of the effectiveness of behavior modification procedures are not susceptible to the serious criticisms leveled against psychotherapy studies. The questions of comparability of samples and of small cell sizes are quite irrelevant because in behavior modification each subject is his own control. Baseline data to determine the level of performance at the initiation of treatment is obtained and this is the yardstick against which progress in acquisition and/or extinction is measured. Furthermore, both the modification procedures and the specific behavioral outcomes are stated in very precise terms. The performance goals are broken down into a series of components, the achievement of each being easily observable and susceptible to objective measurement. Frequency counts are used to determine the extinction of deviant behaviors as well as the acquisition of desired performance skills. As soon as possible, the child in treatment becomes involved in charting his own progress.

This does not mean, of course, that no studies comparing behavior modification are necessary or meaningful. There are many situations in which procedures can be improved or eliminated as a result of carefully designed evaluations. Since the traditional experimental designs are inappropriate, other approaches to studies with handicapped populations must be explored. During the past five years a great deal of progress has been made in the development of new techniques of assessment and analysis. Statistical procedures appropriate for small, heterogeneous samples are being explored. The applicability of the new methodologies to the study of handicapped populations should indeed be tested.

#### 5.0 A THREE-PART PERSPECTIVE FOR THE STUDY OF THE SEVERELY HANDICAPPED

As we focus on the educational rehabilitation of the handicapped child, it becomes increasingly apparent that the dissatisfaction with terminology and categorical descriptions stems from the conflicting purposes underlying the various conceptualizations. A clearer picture of the entire study of deviance would emerge if we could separate three aspects of the problem: 1) prevention; 2) physical-physiological remediation; and 3) educational rehabilitation.

There is no dispute that etiological factors are extremely important in the study of handicapping conditions. They cannot be ignored if we wish to reduce the incidence of handicap in the newborn. Thus, since we know that a mother who has contracted rubella during pregnancy is almost certain to have an impaired infant, research efforts should be made to: 1) determine ways of preventing the occurrence of that disease; 2) increase the likelihood of detecting the presence of the virus during pregnancy; and 3) develop procedures to counteract the effect of the virus after it has been detected, and before the birth of the child.

Two other major causes of mental retardation are the Rh factor and prematurity. The first of these can now be controlled by Rho-gran, a recent biochemical development of the Ortho Pharmaceutical Company. Researches in the cause and prevention of premature births will similarly serve to reduce the incidence of mental retardation and other associated handicaps. In the same way, genetic research would focus on the reproduction process

so that anomalies in chromosomal division can be detected and prevented. Basic research would also be needed for the study of other neurological and organic traumas which are known to be present in severely handicapped children.

Also, the weight of accumulated data from prenatal and perinatal studies, neurological examinations, and electroencephalography, have provided a strong basis for inference that the presence of central nervous system impairment is associated with emotional disturbances. More work must be done to obtain the necessary histopathological evidence which can lead to preventative action programs. Concurrent research is necessary in many scientific disciplines and specializations. The medical-disease model would be appropriate, and investigations would be carried out under the relevant heuristic rubrics. In other words, the concepts and research questions would be categorized and labelled--not the children.

The second line of research is directed toward the amelioration of the physical and physiological conditions symptomatic of the handicap. In this area, a great deal of progress has been made in prosthetic, surgical, and biochemical techniques for correcting the associated physical defects. Many of the most dramatic breakthroughs have been in the area of mental retardation; for example, cretinism has virtually disappeared with the introduction of thyroid therapy.

It has been demonstrated that glandular structures which are genetically determined are functionally related to metabolic and enzymatic processes. There is also a strong body of evidence that the presence of certain protein elements is critical in the development of cognitive ability. Environmental dietary factors may affect the quantity of protein ingested, but the proteins cannot be utilized unless they are broken down by enzymatic action. Where genetic accidents have interfered with the proper development of the glands which provide these enzymes, it is relatively simple to supply whatever deficiencies exist with appropriate nutritional supplements.

The importance of nutrition in maintaining proper growth and development has been known for a long time. However, it is only recently that the really critical impact of diet on the total biochemical balance of the organism has been associated with mental and emotional functioning. Dietary

intervention is becoming increasingly prevalent in the treatment of maple syrup urine disease, and in phenylketonuria, both of which have been associated with impaired mental functioning. It is quite possible that the entire range of borderline and mild mental retardation may be related to heritable factors involved in organic glandular mechanisms having to do with metabolism and enzyme production, both of which are susceptible to dietary and pharmaceutical intervention. A great deal of attention has been given to drug therapy, and the use of ritalin has received wide publicity, while research on the effects of dietary prescriptions to remediate specific deficiencies in nutritional processes has been badly neglected.

Once we have differentiated the two lines of research which deal with prevention and amelioration of the physical manifestations of handicaps, we find it much easier to deal with the educational and rehabilitation problems. For at this point, we are dealing with the performance and behavioral patterns of specific children. We look at the child and determine what his or her needs are, what can be done now, and what still has to be learned. Our concern with needs would of course extend to medical, nutritional, and biochemical prescriptions, but these would not be the basis for assignment to a particular institution or treatment facility.

Research programs in the area of education and rehabilitation would focus on the improvement of a wide variety of procedures and studies to determine under what conditions each is most effective. Educational-therapeutic models based on psychodynamic, social learning, and operant conditioning theories would need to be investigated within the context of new research designs. Questions of causation would be of secondary importance. Of much greater concern would be the emphasis on motivational systems, development of precision and programmed instruction, and careful analysis of tasks into simple components which would maximize opportunities for success.

#### 6.0 FUTURE DIRECTIONS

Most of the new directions in dealing with handicapped children and youth have been touched on in the preceding pages. The most radical of these is an entirely new design for delivery of services.

During the late 60's, a number of specialists in the field of special education became increasingly critical of the existing system. Dunn, Quay, Kirk, Gallagher, Blatt, and other well-known researchers, expressed their dissatisfaction with the underlying assumptions on which the current special education programs were based. They were particularly unhappy with the fact that most special classes and residential facilities were designed to accommodate categories of handicap, e.g. the deaf-blind, mentally retarded, or emotionally disturbed, rather than focussing on the development of needed educational and personal skills.

As a result of these criticisms, several new directions are emerging. The first is the movement to integrate certain types of handicapped children into the mainstream of schooling. Obviously, this is not possible for the most severe levels of handicap. There are, however, exemplary systems in which children with various types of severe handicaps are integrated into day classes within a regular school building. Although most of the program is based on the needs of the individual children, instruction is provided in groups wherever feasible.

The non-categorical approach, new data on the onset of handicaps in the early years, and the incidence of rubella children after the 1964-65 rubella epidemic, provide a basis for a new type of category--"developmental disabilities." There are two facets to this approach: the first is an emphasis on early identification of disabilities; the second is the emergence of preschool programs for the handicapped, stimulated by the Handicapped Children's Early Education Act.

Early identification is particularly important to insure that the various medical, prosthetic, or biochemical-nutritional interventions are introduced before serious primary damage occurs. Amelioration of the primary handicap will also prevent the appearance of secondary cognitive and emotional disturbances which often develop as a consequence of sensory impairments and associated frustrations. Since the most important period for identification of deficits is in early infancy, it becomes the responsibility of pediatricians or well-baby clinic personnel to make perceptive diagnoses.

Some pediatricians tell parents not to worry, that the child will "grow out of it." Where the handicap is particularly severe, others tell the parents that there is no hope; that the child is a "vegetable" and that the sooner it is institutionalized and forgotten, the better. In either case, important and critical time is being wasted during which the child should be receiving ameliorative intervention.

An important first step which will become more and more prevalent in the future will be emphasis on early identification of developmental disabilities. This will be extended into the preschool programs. Preschool and primary grade teachers will be given training in identifying the classical characteristics of various types of impairments (Gotts, 1971; Hammer, 1971; Steele, 1971; Proceedings on Early Education of Handicapped Children, 1972; Papers on the Early Identification of Exceptional Children, 1971).

Technological innovations in cybernetics and man-machine communication systems may offer new ways of reaching the handicapped with sensory impairments. Electronic techniques have also been used to establish communication with mute and non-responsive emotionally disturbed children who do not have actual impairment of sensory modalities. This demonstrates one successful application of the non-categorical approach, which in this case addresses itself to problems of communication regardless of the physical or psychological etiology.

In the future there may be a reversal of the tendency to favor home care over institutional placement. However, the institutional settings will undergo major changes. Personnel such as the "educateur" or the paraprofessional will become more prevalent, and there will be smaller, cottage-type units within the larger institution. Community living arrangements, particularly for the retarded, are proving their viability. The establishment of closer ties between the general community and the residential population promises a healthier relationship for both groups. Supervised trips into town, visits to museums, movies, parks, and ball games, decrease the isolation of the handicapped, and provide increased educational opportunities for both the handicapped and other citizens.

The proliferation of discrete categories of the handicapped has not been conducive to the development of comprehensive service programs. Category

labels have had serious deleterious effects, and many investigators have found that special class placement has contributed to feelings of inferiority and alienation. The future programs for the handicapped will need to discard disability labels and focus on the kind of educational intervention needed. This might be social training, affective or personality development, or the acquisition of specific self-care or academic skills. Training can be given in the regular school context, but it will require master teachers capable of implementing precisely defined programs.

Generally, the trend has been away from the medical-disease model. The most important implication of this movement is that deviant behavior is now being viewed as susceptible to the accepted psychological principles of learning. Several different habilitative programs are being used with some success, but there is very little reliable evidence as to which program is most effective with which type of behavioral problem.

Instead of emphasizing an either-or approach, the future should see the development of a more unified eclecticism, with a strong pragmatic base. Finally, the extension and elaboration of behavior modification seems to offer the most promise for the rehabilitation of severely handicapped children and youth.

## PART II: RESEARCH REVIEW

### 1.0 SEVERE MENTAL RETARDATION

#### 1.1 Problems of Definition and Classification

Of all the areas of handicap with which this review is concerned, that of mental retardation has had the longest history of research and investigation. In spite of this, there is still a great deal of controversy with reference to the basic issues of definition and classification. One source of this conflict is that of multiple orientations. Since mental retardation may be associated with many kinds of events or conditions, individuals exhibiting similar behaviors have traditionally been categorized according to their different underlying etiologies. To some extent this has resulted in important breakthroughs. For example, cretinism has been fading out of the lexicon of mental retardation since its relationship to thyroid deficiency was definitively demonstrated in 1895. Similarly, there has been an increase in the understanding of mongolism, or Down's syndrome. It has been established that this form of retardation is related to certain chromosomal anomalies; however, why these anomalies occur or how they can be avoided is still unknown. (See Gelhart, 1966 and the two reviews of Mongolism referenced in the bibliography.)

While it is understandable that pathologists and medical practitioners should focus on etiological research, since their primary concerns are with diagnosis, medical treatment and, to some extent, prevention, this approach has ultimately diverted attention from the need to develop effective techniques for the training, education, and socialization of those who are currently handicapped by this functional disability. During the past few years there has been a rapidly growing movement, at least on the part of educators, to adopt what has been called a "non-categorical" approach, that is, to design programs which focus on performance deficits regardless of their origins. This would apply not only to mental retardation but also to all types of handicapping conditions.

Adopting such a pragmatic approach does not, however, solve other basic definitional problems, particularly that of determining level or degree of retardation. As Iano (1971) points out, there are important

educational consequences dependent upon whether a child is identified as having a "learning deficiency" or as being mentally retarded. Jaslow et al. (1966) found that the manner in which retarded children are described determines their placement on waiting lists for institutional admission. It is recommended that priority be given to those with the most severe difficulties, such as physical handicaps in combination with neuromuscular deterioration, weight under 35 pounds or requiring tube feeding, asocial behavior after the age of eight, profound retardation after age five, or severe retardation after age four. According to these criteria, 105 of the 300 children under 11 years of age in the Plymouth State Home and Training School should not have been admitted. In other words, these children did not meet the recommended criteria of severity and might have been better off in community or home-based programs, if such facilities had been available.

Pinder (1969) also relates the problems of classification to admission criteria. A survey of 150 state institutions, serving approximately 200,000 residents, revealed that neither the type of impairment nor the level of severity were critical factors in deciding whether a particular applicant would be admitted. Instead, priority was given to those whose presence in the home caused problems with which the family was unable to cope, or aggravated other intra-familial problems. Also, communities often put pressure on institutions to accept applicants who are likely to become delinquents or develop other asocial behaviors.

In the literature surveyed for this report, one of the earliest efforts to establish systematic terminology for use in appraising the mentally retarded was that of a team of specialists at Teachers College, Columbia University (Lorge et al., 1958).

This multidimensional system was later used by Heber (1959) in developing the definitions of the American Association on Mental Deficiency (AAMD), and then expanded at Columbia by many of the same specialists who had been on the original team (Davitz et al., 1964). Seven content areas or bases for classification were considered: etiology; intellectual and educational functions; maturation and social competence; various psychological, physical and environmental factors; and prognosis. In spite of the variety of de-

scriptive characteristics considered, the final decision was to adopt a classification system based solely on one dimension: intellectual functioning. The following categories and IQ ranges were recommended: custodial, IQ below 35; trainable, IQ 35-49; educable, IQ 50-74; slow learners, IQ 75-84. The level below IQ 20-25 was considered "irremediable." It should be noted that these criteria are by no means firm, universally accepted cutoff points. Even in the same communities, variations in terminology are used by different professional groups. Robinson and Robinson (1970), who have an excellent review of research in mental retardation, remark that there are 23 systems of classification in the English language.

Even though the validity of measured intelligence with the severely and profoundly retarded has been questioned, these guidelines have formed the basis for many subsequent classification systems. The persistence of an IQ criterion is probably due to the respect commanded by the work of Binet, the appeal of a neat numerical index, and the inability of psychometricians to develop an acceptable scale of "adaptive" behavior.

The definitions established by the American Association on Mental Deficiency, the Diagnostic and Statistical Manual of Mental Disorders (DSM-11), and the eighth revision of the International Classification of Diseases Adapted for Use in the United States (ICDA) are quite similar (Wilson and Spitzer, 1969). As a matter of fact, the latter two are almost identical, both having been based on the eighth revision of the International Classification of Diseases (ICD-8) developed by the World Health Organization. The major difference between them is that ICDA permits multiple diagnoses whereas under DSM-11 the presence of deficits in intellectual functioning automatically calls for a single and separate diagnosis of mental retardation. This would be true even in cases where the impairment is due to limited sensory input channels, as with deaf-blind children, severe emotional disturbance, autism, or physical impairment of the central nervous system. In essence, DSM-11 adopts the behavioral approach to diagnosis.

The AAMD classification system differs from the two based on ICD-8 in the way in which severity of retardation is recorded, in how the diseases or conditions associated with retardation are described, and in the use of multiple diagnoses. All three systems use the Stanford Binet Test of Intel-

ligence to obtain the IQ score on which classification is based. However, more recently a set of parallel numerical values for use with the Wechsler scales has been developed.

Increasing dissatisfaction with the use of intelligence tests is expressed even by psychometrists, many of whom are now unwilling to accept IQ data as anything other than a very crude estimate of a vague construct. Furthermore, the intelligence quotient is a ratio which is distributed in the population in the form of a continuous scale, so that establishing cut-off points for various levels of normality or abnormality becomes quite arbitrary. As an example, depending on the particular criteria adopted, an IQ of 35 would be considered severe mental retardation, whereas an IQ of 36 would be moderate. Similarly, an IQ of 85 is considered normal, while one of 84 is borderline retardation. Estimates of incidence of retardation can thus be dramatically altered by a whimsical resetting of the criterial number.

Balthazar and English (1969) attempt to develop a system for classifying adaptive and social behaviors of severely mentally retarded patients, but they tie their scales to the AAMD classification system. In his review of the AAMD position on terminology and classification, Clausen (1972) argues against the inclusion of the concept of adaptive behavior in the definition of mental retardation, since he feels that this dimension cannot be objectively measured. He also argues against diagnoses based on etiological or pathological considerations since 50% of mentally retarded persons display no obvious pathology.

Clausen's presentation is the feature article in the June 1972 issue of the Journal of Special Education; the remaining articles of that issue are devoted to reactions to the points made by Clausen. In general, most of the respondents are in agreement with his criticism of the use of adaptive behavior in the definition of mental deficit. However, MacMillan and Jones (1972) point out the dangers of an entirely psychometric definition of mental retardation. Their position is particularly prevalent among the "revisionist" psychologists who distrust both the item content and the process by which the tests have been standardized. They feel that these scales are too highly loaded with learned skills and information and are more

likely to be part of the stimulus background of the Anglo, middle-class child and thus penalize children from ethnic minorities. This would help explain the fact that there is a disproportionate number of minority children classified as mentally retarded.

The supplement to the May 1972 issue of the American Journal of Psychiatry was also given over to the subject of classification in mental retardation. It is based on a 1969 seminar series co-sponsored by the World Health Organization and the National Institute of Child Health and Human Development. Ewalt (1972) expresses concern with the fact that the British and U.S. concepts of mental retardation differ so drastically that a uniform international classification system becomes impossible. The British define mental retardation as an arrested or incomplete development of the brain, and thus an absolute and immutable condition, while in the United States it is considered a measure of mental functioning at a given time, hence subject to change. It is interesting that this definitional difference between Britain and the United States corresponds to Doll's distinction between mental deficiency and mental retardation.

Without exception, all the contributors express dissatisfaction with a completely psychometric standard, that is, one based solely on an intelligence test score. Tizard (1972) suggests that the ICD classification be revised to provide a multiaxial system which would permit the integration of categories used in child psychiatry, developmental neurology, and mental retardation. He also recommends elimination of the "unspecified mental retardation" category used with non-testable patients, expansion of the medical axis, consistent identification of patients with both severe emotional disorders and symptoms of mental retardation, development of a useful indicator of sociocultural retardation, and the inclusion of additional physical handicap categories in the mental retardation classification scheme.

Although Tarjan et al. (1972) also recognize the limitations of intelligence tests and argue for a multifaceted approach which would include other considerations, such as social competence, they concede that "given care and attention to detail, an IQ test remains the best way of making comparative judgments of intellectual ability within a given culture."

## 1.2 Prevalence Studies

Almost equal in importance to the development of meaningful bases for categorizing the various levels and dimensions of retardation is the determination of the parameters of need in the field of severely and profoundly retarded children and youth. Many of the surveys addressed to the collection of statistics on the prevalence and incidence of mental retardation are also concerned with the adequacy of existing facilities for serving the estimated population; others are concerned primarily with providing a basis for planning future programs and resources. For example, one of the earliest surveys of the national incidence of mental retardation covered in this literature review, carried out by the Public Health Service Committee (Graning, 1964) on the mentally retarded, included principles for planning and an outline of planning procedures.

Heber (1970) provides figures on the incidence of need by age, across geographical regions within the United States. The statistics include breakdowns by racial and ethnic groupings, economic class distributions, family variations, and population distributions in institutions. In a national survey carried out for the Rehabilitation Services Administration, Jaslow (1970) presents trend data, patient movement ratios, and personnel and financial information for public institutions serving mentally handicapped persons during 1963-1969. Figures are listed for each category by individual states.

During the middle sixties, when each state was required to develop a plan to deal with mental retardation, prevalence and incidence rates played an important role in establishing the need for new services. Florida was one of the first states to take a systematic look at its mentally retarded population. The Florida Plan for Comprehensive Action to Combat Mental Retardation (1965) is based on the American Association on Mental Deficiency (AAMD) definition of mental retardation: "subaverage intellectual functioning which originates during the developmental period and is associated with impairment in adaptive behaviors." The Florida Plan also uses the AAMD's classification scheme in determining the following estimates of prevalence: educable, 2.5%; trainable, 0.4%; custodial, 0.1%. The latter category includes the profoundly retarded (IQ 0-24) and the severely retarded (IQ 25-39).

Similarly, the West Virginia Commission on Mental Retardation, in A Plan Called Promise (1966), also uses the AAMD definitions and sets the general incidence of mental retardation at 3%. The New Jersey Comprehensive Plan to Combat Mental Retardation (1966), which reviews a number of prevalence studies conducted from 1929 through 1963, cites a wide range of incidence, from 0.68% to 8.83%. The prevalence findings for severe retardation agree with those of the AAMD estimates, being only 0.1% of the population.

Payne (1971) reports a prevalence survey of severely mentally retarded children in Wyandotte County, Kansas, which used an IQ of 50 as the cut-off point. Incidence rates were 1.39 per 1,000 among children five years of age and under; 5.94 per 1,000 among children and youth between the ages of five and nineteen; and 1.13 per 1,000 among the population twenty years of age and older. These figures are higher than rates found in other similar studies, which are summarized in the article. Blatt and Garfunkel (1971) have done a survey of need for various handicapped children in the Commonwealth of Massachusetts, and Sarason et al. (1971) report the work of the Central Connecticut Regional Center in estimating need prior to its creation of a community setting for retarded persons in that state.

A prevalence study currently under way in Pennsylvania is called COMPILE, the Commonwealth Plan for Identification, Location, and Evaluation of Mentally Retarded Children, 1972. This project is designed to identify, locate, and evaluate all school age children who either are, or are thought to be, mentally retarded. In accomplishing its objective of developing a comprehensive listing of such children, several survey strategies are being used. These include house-to-house canvassing to identify and locate retarded children, and intensive two-month statewide public education campaign to provide maximum support to the effort, and a 24-hour toll-free telephone service for reporting children not in school.

Mayeda (1971) while primarily concerned with the delivery of services also provides information on the number of mentally retarded children and adults in California, Colorado, North Carolina, Ohio, and Washington. His statistics include the number of residents in state institutions and the number of those residents per 100,000 population; the number of 24-hour care community placements and the number of such placements per 100,000

population; additionally, the report furnishes the number of enrollees in special education classes, a census of sheltered workshops, and costs associated with each.

Robinson and Robinson (1970) take the position that it is almost impossible to obtain a definitive answer to the question of statistical prevalence of mental retardation. In the first place, the definition of what constitutes retardation varies across countries and circumstances of life. Thus, in the United States alone, estimates have ranged from .05% to 13% since the first census in 1894. Levels of mental ability which are adequate in an agrarian society become inadequate under pressures of an industrialized society with greater demands on literacy and abstract functioning.

### 1.3 Research and Demonstration

1.3.1 Behavior Modification with the Severely Retarded. Much of the literature on severely retarded children and youth is concerned with the application of operant conditioning or behavior modification techniques. Although a number of studies focus on other topics and concerns such as Down's Syndrome, comparative effectiveness of home vs. institutional environments, development of assessment procedures for measuring the capabilities of this population, and the evaluation of other treatment methods, operant conditioning has provided the greatest single impetus for research and experimentation. Whereas 10 years ago severely and profoundly retarded children would not have been of interest to researchers, today there are numerous studies with this special population.

The present review covers mainly the most recent work in this area. For those who wish a longer perspective, an annotated bibliography on behavior modification with children and adults, developed by L'Abate and Whitaker (1967), lists and summarizes 130 journal articles and books published in the 1960's. Similarly, Graziano (1971) has compiled a series of 39 papers, many of which concern behavior therapy with severely mentally retarded children. In all those studies in which behavior modification has been properly used and controlled, there is unequivocal evidence that even the most profoundly retarded can profit from instruction and training.

Because of the increasing importance of this technique, and because so much adverse publicity has been generated by the writings of B.F. Skinner, who formulated the psychological theory on which operant conditioning is based, a researcher in the field of special education needs an objective orientation to behavior modification procedures. There are, of course, countless expositions in this area, but the series of three articles by Nawas and Braun (1970) is particularly relevant for those who work with retarded children. The first article presents the fundamental steps which must be taken in the initial phases of an operant program, while the second article discusses the procedures and concepts in greater detail. Among the topics elaborated are: positive reinforcement, avoidance and escape procedures, imitation, extinction, fading or gradual removal of reinforcers, punishment, and time-out. The basic principles of reinforcement theory are presented, with their application to retarded children wherever possible. An important point is that operant conditioning must be an on-going process within the context of every-day activities and not just applicable during special periods. After sufficient exposure to the conditioning process, desired behaviors become self-sustaining and require little tangible reinforcement.

The effectiveness of behavior modification procedures has been most strikingly demonstrated in the training of self-help skills such as toileting, dressing, and self-feeding. Of these, perhaps because incontinence creates so many maintenance problems and is so demoralizing to institutional staff, the inculcation of appropriate toileting habits has received by far the largest measure of attention. Generally, two types of studies have been carried out in this area. The traditional operant conditioning experiment establishes a base line of behavior before the reinforcement procedures are introduced, and then tracks the progress in acquiring desired or eliminating inappropriate behaviors, whereas more conventional research designs contrast the effectiveness of different treatments or one treatment condition with a control group.

The toileting experiment carried out by Bates and Armenti (1970) falls into the second category. This study compared the attractiveness of several types of reinforcers in the acquisition of appropriate toileting behaviors

with 11 profoundly, severely, and moderately retarded males. Music, candy, cold drinks, and television were offered as tangible reinforcers to the experimental group while a control group received only verbal rewards. Among the tangible rewards, candy and music were selected as reinforcers 82.8% of the time. However, all those who received a tangible reward demonstrated a significantly greater number of successful toilettings than those who received only verbal approval. No differences were related to level of retardation. Roos and Oliver (1969) also demonstrated that severely retarded children made significantly greater improvement, not only in toileting but also in other self-help areas, under operant conditioning training than with more traditional procedures.

Many of the toilet-training experiments are of the operant conditioning variety. Thus, Baumeister and Klosowski (1965), Levine and Elliott (1970), Azrin and Foxx (1971), and Azrin (1971) have all demonstrated the effectiveness of reinforcement procedures in eliminating incontinence in a relatively short training period. The latter Azrin study is particularly interesting in the use of two devices, a portable pants-alarm and a toilet chair, in facilitating immediacy in the contingency management process.

Minge and Ball (1967) successfully established toileting skills with six profoundly retarded girls (IQ 10-24), and then proceeded to teach the girls to bathe, groom, and dress themselves. This was accomplished in two individual 15-minute training periods per day over a two-month period.

In a program developed by Berkowitz et al. (1971), self-feeding skills were taught to 14 profoundly retarded boys who had never spoon-fed themselves. The time taken ranged from two to sixty days, but eventually all the boys learned these skills. Balthazar et al. (1970) also applied operant techniques to improve eating skills of institutionalized profoundly and severely mentally retarded children, with only secondary emphasis on dressing and toileting.

Behavior modification techniques have also been used in developing more complex behaviors. A number of researchers have used these methods in the training of perceptual motor skills (Hollis, 1967), positive social interaction (Paloutzian, 1971), and attending behavior. Severely retarded children were taught to attend to classroom stimuli, regardless of intrinsic

interest, and to increase their levels of social behaviors in a ward setting (Brown and Foshee, 1971). Gray and Kasteler (1969) demonstrated that institutionalized retarded children can improve their social competence when older men and women, such as in the Foster Grandparents Program, provide appropriate models and reinforcers. Using positive reinforcement, physical guidance, and the gradual removal of tangible reinforcers, Whitman et al. (1971) determined that severely retarded subjects showed pronounced increases in both trained and untrained instruction-following behaviors. Crosson and DeJung (1967) used Skinnerian principles of shaping, operant discrimination, and chaining of responses to train residential retarded persons on selected vocational tasks. Results of the study indicate that extrinsic reinforcement maintains higher and more stable rates of vocational behavior than does social reinforcement. Music is a reinforcer which has proven consistently effective. In two experiments conducted by Jorgenson (1971) the contingent presentation of music was found to reduce the duration of both hand movement and rocking behavior in a 10-year-old profoundly retarded girl.

Many other examples of the successful use of behavior modification with severely and profoundly retarded children and youth can be found in the literature (e.g., Minge and Ball, 1967; Provencal and MacCormak, 1971; Scheerenberger, 1969; and Vails, 1970). Some questions have been raised as to the long-range retention of behaviors learned in this fashion. Leath and Flournoy (1970) carried out a follow-up study of an intensive habit-training program. They found that three years after a relatively brief shaping program, the learned behaviors were maintained without any intervening retraining. No changes were found in the complex social and communications skills taught, whereas a significant gain in eating skills was demonstrated.

In order to maximize the success of a behavior modification program, a number of investigators have combined reinforcement procedures with other types of facilitating manipulations. For example, Roos (1965) and Kimbrell et al. (1967) combined behavior modification techniques with environmental manipulation to increase the effectiveness of their training programs. Special clothing, equipment, and utensils made it possible for profoundly

retarded patients to maintain continence and independence in their basic life functions.

Baker and Ward (1971) describe a program in which reinforcement procedures were applied in a total milieu approach. Six profoundly retarded persons received training in self-help skills, as well as intensive therapy, while living in a small, home-like unit. The criterion measures used to evaluate the progress of the subjects and a matched control group of ward residents included the Peabody Picture Vocabulary Test, the Denver Developmental Screening Inventory, behavioral observations, and staff records. The treatment was assessed as generally effective, although less success was obtained with emotionally disturbed persons.

Gorton and Hollis (1965) also combined operant training procedures with modification of the environment. A cottage unit at a state institution was redesigned according to a cubicle system which facilitated the social interaction of the residents. In addition to the architectural modifications, a 12-session program was conducted to train aides in the application of reinforcement principles.

Another technique for maximizing the effectiveness of behavior modification training is to train parents and those institutional staff who come into daily contact with the children to continue the reinforcement procedures outside the classroom. Thus, Blumberg (1971) describes a program which trained parents of 25 profoundly and severely mentally retarded children to use operant conditioning techniques in teaching their children self-help skills at home. This involved a three-day workshop and the filming of parent training sessions for evaluation and feedback. Instructions taped by professionals were used by Scoggins et al. (1971) to increase the scope of effective teaching in programs for severely and profoundly mentally retarded children. The tapes presented the behavior modification approach to the teaching of self-help skills, language, and good work and play habits necessary to prepare residents for sheltered workshop participation. Connor et al. (1972) prepared pre-recorded audio tapes to train non-professional group leaders in the use of behavior modification techniques in various instructional programs. Similar techniques were used by Bennet (1966) in the training of staff. To raise the language skill levels of 100 mentally

retarded institutionalized children, any attempts on the part of ward personnel to stimulate these skills was rewarded. The results showed significant gains in the language skills of the residents, as measured by the Parsons Language Sample and the Verbal Language Development Scale.

An intensive training program in which behavior modification techniques were used with both patients and their parents was developed by Fingado et al. (1970). During a 30-day period of institutionalization, a team of nursing and psychology personnel developed individualized behavior modification programs for each child and also taught the parents to carry out these programs when the children were returned to their homes. Follow-up to maintain the procedures was provided.

The results of these studies have broad implications. Far more important than the immediate enhancement of the behavior modification training is the encouraging evidence that parents and non-professional provider staff can successfully implement operant conditioning programs after a relatively brief training period. With the increasing tendency to favor home-care placements for severely retarded children, it is comforting to know that there is this excellent reservoir of potential teachers.

1.3.2 Aversive Stimuli in Behavior Modification. For a long time one of the cardinal principles of operant conditioning has been that only positive reinforcers produce lasting changes in behavior. Shaping procedures are based on the premise that elements of the desired behavior will be spontaneously emitted, at low rates of frequency, and that the immediate presentation of a positive reinforcer will increase the frequency of that behavior. The presentation of a punishing or aversive stimulus, or the withholding of a positive, desired reward, was considered negative in that it did not teach what to do but rather what to avoid. Even then the effectiveness of the training was thought to be transitory, with many deleterious emotional side effects.

Unfortunately, the major problem in the rehabilitative training of severely mentally retarded and emotionally disturbed individuals is the elimination or extinction of undesirable or aberrant behaviors. (For a definitive treatment of the rationale and research in the use of aversive

stimulation with severely retarded and disturbed children, see Gardner, 1970.) Although it is sometimes possible to manipulate the environment so as to eliminate the conditions which reinforce these behaviors, most frequently the stimuli which initiate the deviant behaviors are internal and cannot be anticipated. If undesirable behaviors are being emitted at a high rate of frequency, the opportunities for reinforcing the desired behaviors are accordingly minimized. Furthermore, the occurrence of inappropriate responses (e.g., self-mutilation, head banging, biting, temper outbursts, etc.) constitute a hazard to the well-being of the person emitting the behaviors as well as to those about him. Thus the first task of the behavior management program is to eliminate or extinguish the undesirable behaviors.

In the first applications of behavior modification theory to this population, the technique of extinction was used to eliminate aberrant behaviors. The withholding of positive reinforcers was paired with the presentation of the opportunity to obtain reward for a desired response (e.g., Girardeau and Spradlin, 1970). This approach, if it is effective at all, takes a long time and meanwhile serious injury and disfigurement may occur. Thus a number of researchers have turned to the use of aversive stimuli, and have found little evidence of persisting negative emotional affect. On the contrary, White and Taylor (1967), in the study reported below, note that the experimental procedures themselves offer a means for fostering interpersonal relationships since both subjects showed greater awareness of and appeared to interact more with the experimenters than with regular staff.

Kirchner (1971) reports two experiments in which children given electric shock treatment tended to produce better performance as measured by a decrease in inattentive behavior and a higher ratio of correct to incorrect responses. Corte et al. (1971) found contingent electric shock stimuli more effective in extinguishing behaviors such as head banging and face scratching in four institutionalized profoundly retarded adolescents than mild food deprivation. In the White and Taylor (1967) study two severely retarded adolescents were administered electric shock in order to eliminate vomiting after meals. The aversive stimulus was presented as soon as pre-

ruminating gestures were initiated. On occasion other variables acted as distractors to forestall vomiting, and it was hypothesized that these life-long patterns were highly influenced by ward routines and the quality of interpersonal interactions. Although the data reported in this study are inadequate for a definitive statement, there is some evidence that the presentation of electric shock significantly reduced the frequency of ruminating behavior. It should be pointed out that in a number of studies which investigate the effect of differing intensities of shock, many cases of adaption to shock occur and mild shock may even become reinforcing. Also, where the remission of the inappropriate behavior is not used as an opportunity for replacement with reinforced desired behaviors, recurrence of the extinguished behavior is not infrequent.

1.3.3 Other Training and Rehabilitation Approaches. In addition to behavior modification, music therapy, sensory awareness training, environmental manipulation, and a variety of stimulative techniques have been used in establishing sensory-motor behaviors, posture and locomotion, articulation, and expressive and receptive language behaviors. Severely retarded, self-mutilative boys were exposed to periods of both sedative and stimulative music which was piped into their institutional environment. The result was a decrement in activity levels and self-mutilative behaviors (Reardon and Bell, 1970). This study also confirmed the hypothesis that stereotypic behaviors provide needed stimulation to children who are stimulus deprived. One practical application of these findings would be to bring stimulating music into wards which have a large number of hyperactive retarded children, so as to modulate their activity level.

Another form of sensory stimulation was used by Webb (1969), working with profoundly retarded encephalopathic children. Movement activities, manipulation of the physical environment, and posture and locomotion training were provided for a period of five to ten months. While all children showed improvement in sensory-motor behavior, the most noticeable gains were made by the younger children who were relatively free of physical deformities and disruptive behavior patterns.

The stimulus environment of the institution, in terms of its effects on speech development, was examined by Haviland (1972). Appropriate visual,

auditory, tactile, and kinesthetic stimuli were suggested along with recommendations for the removal of inappropriate stimuli, such as noise levels of high intensity which are disruptive and interfere with speech communication.

A number of educational alternatives have been explored. The Instruction Guide for the Profoundly Mentally Retarded (1968) is one of a number of such manuals prepared for teachers and institutions working with this population (e.g. Bramley, 1970; Gardner and Nisonger, 1962; Happ, 1967; Lobenstein et al., 1964; Stevens, 1971). Curricula have also been developed for training severely mentally retarded persons in language skills. Chalfant et al. (1970) field tested the Systematic Language Instruction (SLI) curriculum, which utilized behavior modification, task analysis, and errorless learning. They found that students using SLI made significant gains in language, self-care, and motor performance over children exposed to different curricula. Hallet et al. (1971) describe a program to teach functional language to severely and profoundly mentally retarded children. Innovative programs providing vocational training have also been developed (e.g., Reece, 1972; Revall, 1972).

Other techniques described in the literature include a mobile unit for delivering educational services to Down's Syndrome infants (Rynders and Horrobin, 1972), a technique for building effective behaviors in profoundly retarded children through close body contact and physical stimulation during intensive play (Bradtke, 1972), psychiatric approaches (Menolascino, 1970), group therapy to train severely mentally retarded adolescents to work together (Chigier, 1971; Forman, 1970), the use of group dynamics in a preschool child-care center (Broms, 1971), audio tapes which offer intensive programming for groups of severely and profoundly mentally retarded children (Connor et al., 1972), and music therapy to develop speech skills of institutionalized severely mentally retarded adults (Walker, 1972).

#### 1.3.4 Research on Severely Retarded Children with Down's Syndrome.

Because there are so many papers dealing specifically with Mongolism or Down's Syndrome, a discussion of research with this segment of the severely retarded population is provided in a separate section. However, it should

be emphasized that this is purely a heuristic convenience and that in actuality the treatments and findings in these studies do not differ substantially from those of studies with other retarded persons functioning at the same level of mental competence. Johnson and Olley (1971) reviewed the literature of Down's Syndrome to determine the utility of the AAMD's classification, and found numerous studies comparing the experimental task performance of this group with that of other retarded children. There was little evidence that performance on the experimental tasks is related to the medical classification; furthermore, there were more similarities than differences between Down's Syndrome and non-Down's Syndrome retarded children.

A paper prepared by the National Institute of Neurological Diseases and Stroke on the subject of Down's Syndrome (Mongolism, 1971) includes a brief description of the etiology and diagnosis of this genetically transmitted condition. Although a number of research reports are cited, the need for a great deal more research in this area is emphasized.

In a study of 44 home-reared Down's Syndrome children, Cornwell and Birch (1969) found that the Stanford Binet IQ decreased with age whereas the Vineland SQ (Social Quotient) did not decline as systematically. The data support the hypothesis that Down's Syndrome produces both a developmental lag and an arrest of certain psychological and social capabilities. A programmatic study carried out by Rhodes et al. (1960) demonstrates that language stimulation and articulation training produce sharp improvements in expressive and receptive language and articulation; there are also significant increases in intellectual ability, and in the ability to read and enjoy simple books. In addition, the children exhibited decreases in destructive, random, and stereotypic acts and asocial behaviors.

Another group of Down's Syndrome children were placed in an experimentally enriched setting including a one-to-one adult:child ratio with continuous exposure to stimulating and physically strengthening experiences as well as a home-like atmosphere. These children exhibited progress in sociability and adaptability, gross and fine motor skills, language development, and self-help skills (Kugel, 1970). The author concludes that institutionalized mentally retarded children can develop well socially and intel-

lectually if provided care and stimulation in a home-like environment. Fredericks (1969) compared the effects of the Doman-Delacato method with behavior modification procedures in improving the coordination of 72 children with Down's Syndrome, ages 7-12. At the end of nine weeks there were no significant differences between the treatments.

1.3.5 Mentally Retarded and Multiply Handicapped. The comparatively few studies on multiply-handicapped retarded children are extremely diverse and range from concern with the care of physically handicapped retarded children to speech and language habilitation in the severely mentally retarded.

Melcher (1966) reviewed activities to be used by professionals and parents in working with children who are severely retarded and physically handicapped. The author feels that state agencies can make important contributions in five areas of concern, including provision of:

- workers with a real conviction that multiply-handicapped children can learn and achieve;
- effective community based administrative devices to ensure continuity of planning and services;
- educational content in activities;
- guidance and counseling for the family; and
- employment of an itinerant home teacher-counselor to work with children who are unable to attend special school programs.

Forty-one studies on the incidence of speech and language problems in the mentally retarded were reviewed by Keane (1972). These studies indicate a higher than normal incidence of speech, language, and hearing disorders. Institutionalized retarded children tend to exhibit more communication problems than the non-institutionalized, with a high negative correlation between IQ score and frequency of severe communication problems. No unique pattern of speech deficiency has been demonstrated in the mentally retarded as a whole, although articulation, voice, and stuttering problems are, in that order, the most prevalent source of speech difficulties in retarded persons.

A method of communication for severely retarded, multiply handicapped, non-speaking children is described by Levett (1969). The system was used with a group of 5-to-16-year-old children who, in addition to being mentally subnormal and cerebral palsied, were also deaf, partially sighted, and afflicted with perceptual problems and severe motor dysfunction. A system of mime was developed after the use of pictures, the written word, finger spelling, and sign language all proved ineffective. The mime system involved the teaching of approximately 100 words through appropriate gestures. No data as to the effectiveness of the method was available.

Burland (1971) maintains that severely retarded children can show normal verbal regulation of behavior and that non-verbal thought in this population can reach a 12-year developmental level with verbal abilities at the preschool level. Thus differential rates of maturation in the verbal and non-verbal systems can be expected when developmental discrepancies exist between the two.

1.3.6 Home and Institutional Care Programs. The advantages of home care vs. institutional placement have been investigated by a number of researchers. Several studies have also considered the effect of a severely retarded child on the other members of the family. One such study (Fotheringham et al., 1971) was designed to test whether the presence of a retarded child in the home results in a measurable increment in family stress. The findings indicate that institutionalized children, because of their low social maturity and high incidence of socially disruptive behaviors, were more stressful to their families than similarly retarded children who remained at home. However, families who chose to institutionalize their children were more apt to be of a lower socioeconomic status than families who kept their children at home, and the functioning of children from similar SES backgrounds was apparently at the same level regardless of their living situations. For both SES groupings, family functioning did not improve even after the disruptive child had been out of the home for a year.

In a study by Kershner (1970) it was found that families who kept their retarded children at home showed decrements on a number of social adjustment criteria, while families who institutionalized their children tended to

improve over a 12-month period. The effects of a severely retarded child upon the family were related to the age, sex, and dependence of the retarded child, as well as to the presence of normal siblings and the social status and religion of the family (Farber, 1959). Farber suggests that having in the home a retarded boy, especially one over the age of nine, will probably be associated with one or more of the following: discordant parental marital relations, personality problems in the sister who is given responsibility for the retarded boy, and personality disturbances in normal siblings.

Francis (1971) studied four groups of children, both normal and Down's Syndrome, who were either reared at home or in an institution. Comparisons of the groups indicate that institution-reared normal and Down's Syndrome children were behaviorally more retarded than their home-reared counterparts of the same chronological age.

In contrast, Rosen et al. (1966), in a study of the expectancy of success in the self-evaluations of moderately-handicapped retarded children, found that institutionalized subjects consistently set higher estimates of performance for themselves and are more confident of ultimate success than are matched non-institutionalized subjects. The study supports the contention that residential care is more conducive to optimism and self-confidence than the regular school and community setting.

Klamer (1969) conducted a study of six residential institutions in order to demonstrate that institutions are different from each other, to show that these differences are directly responsible for differential functioning among the residents, to identify reasons for differences, and to recommend changes in institutional management which might lead to the maximum realization of developmental potential of the residents.

Two of the six institutions were judged to be ineffective since the residents appeared to be unhappy and dependent; they showed little intellectual growth, exhibited many stereotypic behaviors, and manifested excessive need for social reinforcement. One institution emerged as clearly effective and one as moderately effective. In five of the six institutions, other ward residents were the greatest source of interpersonal contacts; in only one institution did attendants and other non-retarded adults interact.

frequently with residents. In the typical institution, between one-third and one-half of the time of the severely retarded was spent in idleness. Attitudes of attendants and parents of the children in the different institutions were remarkably consistent; however, in the two institutions judged to be most effective, parents visited their children more frequently.

Kurtz and Wolfensberger (1969) reviewed the reasons for separation of residents from a midwestern state institution for the mentally retarded between 1910 and 1959. They determined that death was the most common cause, with the highest proportion of deaths occurring during the first three to twelve months following admission. It was also found that residents who entered the institution during adolescence were far more likely to be released into the community than persons admitted prior to adolescence. Early institutionalization therefore seems to decrease the mentally retarded person's chance of release from the institution.

A longitudinal study of institutionalized retarded persons conducted by Vogel et al. (1968) examines the effects of environmental enrichment, and the relationship between cognitive functioning and adaptive behavior. Exposure to the enriched environment by the experimental group produced significantly greater gains in personal skills but made no difference in the acquisition of social skills. In both the experimental and control groups, mental age was related to acquisition of personal skills, but not to social and emotional behavior.

Klabeř et al. (1969) suggest that the effects of institutionalization in a deprived environment may be reversible. Two institutions, whose major differentiating characteristic was the degree of social interaction offered to the children, were compared. A group of severely retarded children was transferred for administrative purposes from the more depriving institution to the institution which offered a greater opportunity for social interaction. Results indicate that children remaining in the more depriving institution approached closer to, and elected to stay longer with, a socially reinforcing adult than did the children who had been transferred. Furthermore, they suggest that heightened responsivity to a caretaker may become associated with heightened reaction to socially-defined failure experiences and may interfere with independent problem-solving behavior and therefore with intellectual development.

The Pygmalian effect of teacher expectancies has been demonstrated with normal school children (Rosenthal and Jacobson, 1968). Soule (1972) was interested in learning whether a similar phenomenon would occur when cottage parents were given misleading information about retarded children. However, no difference in performance attributable to the experimental treatment could be observed. While the author concludes that this demonstrates "no effects of teacher bias," it may very well be that the custodial relationship is such that the behavior of the caretaker is not altered by the knowledge that one group would do better than another.

In another study of children in a custodial environment, two groups from presumably similar custodial buildings of a large public institution were observed under controlled conditions for several months to determine each child's skills and deficiencies (Barrett, 1971). Unexpected behavioral differences between the two groups were found to be associated with differences in characteristics and practices of building employees. The children who proved to be more disruptive and slower to respond to treatment were housed in a building with younger staff, including some male employees, with an average of 13-1/2 years of experience in the institution. Most of the children in this building were still in cribs and were treated as infants regardless of their age. In addition, children housed in this building were notably over-protected; no attempts were made by the staff to teach them self-care skills; and the staff "pets," for whom the staff did as much as possible, were at the lowest level of development.

The children who proved to be least disruptive and who responded most favorably to treatment were housed in a building with all-female staff having an average of 4-1/2 years of experience in the institution. The staff-child ratio in this building was lower than in the comparison building, and there was a more chaotic atmosphere. In addition, the matrons on this ward applied behavior modification techniques to teach children to be more self-sufficient and there was a higher staff turnover, which was felt to be advantageous to the children's development. This study raises important questions of behavioral requirements, staff-child ratios, inservice training, and rehabilitative procedures for caretakers. These questions must be addressed by administrators and researchers who wish to improve residential services for the retarded.

The introduction of behavior modification units within the institutional context is becoming more and more prevalent. One of the innovators in this area is the Pacific State Hospital in California. Ball (1969) describes the implementation and administration of their program, and provides guidelines for staff training, selection of patients, operation of the token economy, the education program and, with special interest to this study, the development of new programs in ward care for the most severely retarded.

Community-based care programs are seen as alternatives to institutionalization. Meyer (1972) describes a program which provides weekly residential care in a family setting for a group of severely retarded elementary age children. The normality of the home environment and the low staff-child ratio are cited among the program's advantages. These are also the advantages advanced by proponents of foster care for mentally retarded children. Adams (1970) provides a brief review of residential care in institutions and compares this type of service with that of placement in foster homes. The problems of foster home placement and administration are not minimized by the author. The team approach in foster care programs is presented by Green (1972). Curfman (1967) discusses a homebound therapy program for severely retarded children and their families. The program, consisting of occupational therapy for the children and counseling services for the parents, assesses and develops the child's potential and helps the family understand the child and contribute more to his development.

Some innovative school systems have set up special programs located within the regular school buildings. For example, operant procedures have been the basis of "engineered classrooms" such as those of Hewitt (1968) and Kokaska and Kokaska (1971), among others.

Finally, there has been a trend in the last few years to place some exceptional children in regular classrooms. An early experiment by Hayes (1969) demonstrated that this type of integration could be successful in a day camping program. Since then, a number of school systems have integrated mentally retarded children into their regular programs. Reports of these efforts can be expected to appear in the literature in the near future.

With the increased emphasis on caring for severely retarded children in their own or foster homes, a new area of need has become apparent. The

strain on the parent-caretaker of a severely retarded child is considerable, and some means for temporary relief must be made available. McKibben (1972) discusses an interdisciplinary program which provides counseling and support services in such situations, and Paige (1971) develops the concept of "respite" care for parents charged with full-time responsibility for a retarded child. Respite services include homemaking, nursing, and baby-sitter services, as well as foster care, temporary care, family-group, and group homes.

#### 1.4 Measurement

A number of investigators have been concerned with the measurement of IQ, SEQ and other areas of functioning in the severely mentally retarded. There is a great deal of dissatisfaction when standard measures of functioning are used with the severely and profoundly retarded population. Parker (1971) states that identifying and classifying mental retardation is confounded by the fact that an apparently normal distribution of intelligence levels may result from the technique of test construction alone. An appropriate test, according to Parker, would be one which produced a bi-modal curve discriminating the critically retarded from the non-critically retarded. Parker maintains that the major difficulty in measuring intelligence stems from the difference between cognitive capacity and empirical problem-solving ability. He indicates that intelligence assessment must be closely related to the individual's environment, with "culture fair" items needed to assess the individual's growth and development. Several studies conducted to determine the reliability and meaningfulness of IQ scores of individuals with IQ's less than 30 were reviewed by Ross and Boroskin (1972). In each study, over 130 severely retarded individuals were tested and it was determined that the lowest correlation between IQ and behavioral age was .77. The conclusion that IQ's below 30 can be both reliable and meaningful in behavioral terms has not, however, received general support.

Allen and Allen (1967) developed a compendium of instruments commonly used to evaluate the intellectual capabilities of children suspected to be mentally retarded. The resource book is intended for use by practicing

psychologists and contains information on all aspects of tests and testing of the mentally retarded, including reviews of standardized intelligence tests such as the Stanford-Binet, the WAIS and the WISC; developmental scales for preschoolers; figure drawing, picture vocabulary, formboard tests; and a variety of non-verbal paper and pencil tests of intelligence. Other specialized tests, such as the Frostig, ITPA, and third person assessment measures, are also included. Grace et al. (1959) attempted to develop a series of learning tests which would provide objective, quantified, predictive measures of the educability of severely retarded children (IQ below 50) and which would relate test performance to significant aspects of life behavior. All the tests in the battery, intended for use with subjects aged 5 to 11 years, were short, non-verbal, and not dependent on past experience. Results of the analyses showed that the tests were appropriate to the ability of the subjects; they were able to arouse and hold their interest, and were suitable for children with severe verbal and physical handicaps. It was determined that intelligence exerted a more significant effect on the scores of every test than did factors of age, time spent in school, sex, or medical diagnostic category. The relationship between learning performance and intelligence level was significantly greater on every test than that of intelligence level and initial performance.

Another group of authors examined the relationship between intellectual level and social and emotional behavior (SEB) in an institutionalized population including randomly selected subjects from among the moderately, severely, and profoundly retarded groups (Gardner and Giampa, 1970). The three groups of retarded children did not differ significantly in inappropriate social-emotional behaviors, indicating that the affective and cognitive areas are relatively independent and hence require separate measurement. Silverstein (1971) examined the reliability and constancy of Fisher and Zeaman's K for measuring the intelligence of institutionalized retarded children. In contrast to the ratio IQ and the deviation IQ, K proved to be relatively constant over test-retest intervals of six to seven years. A study by Halpern and Equinozzi (1969) showed that IQ predicts those aspects of adaptive behavior which relate to academic success, while the Verbal Expressivity Scale predicts those behavioral aspects which relate to skill in communica-

tion. The hypothesis that verbal expressivity and intelligence are relatively independent of each other and that they do predict different aspects of behavior is supported. Friedlander et al. (1967) developed an automated operant conditioning device called PLAYTEST, which could be attached to an ordinary playpen. The device measures the sensorimotor manifestations of attention, purposefulness, response selectivity, and adaptive behaviors. Friedlander used PLAYTEST with two severely retarded boys aged 2.5 and 3.5, with mental ages below 10 months. He reports that, in evaluating sensorimotor abilities with severely handicapped infants, the device offers advantages over more traditional methods such as normative developmental scales, numerical developmental quotients, and other techniques typically used with "normal" children. The author emphasizes that PLAYTEST allows the examiner to observe the skills and abilities in addition to the disabilities in the sensorimotor domain.

Husted et al. (1971) used two forms of the Cattell Infant Intelligence Scale with 40 severely retarded children to determine whether lack of predictive validity in infant intelligence tests is due to lack of interest on the part of the child. Half of the children were given candy reinforcers and scored significantly higher in both mental age and IQ than did the group which received only the regular test materials. The investigators suggest that the candy produced increased motivation and consistency of response, thus affording a clearer picture of the cognitive abilities of the child being evaluated.

#### 1.5 Standards for Residential Care

Goals of institutional care for the retarded have changed over the years as the philosophy of the mental retardation movement has evolved. Younie and Goldberg (1970) have traced the changes in residential care, noting the following progression in goals:

- Make the deviant undeviant;
- Shelter the deviant from society;
- Protect society from the deviant; and finally,
- Help each mentally retarded individual learn as much as he is capable of learning so as to realize his full potential.

Another historical review of the development of institutions for the mentally retarded is provided by Wallin (1966). The focus is on trends in diagnosis, classification, and treatment in both the United States and Europe since 1900. Of particular interest to educators is a section on the creation of the special education category within the public school system, together with the legal and parental efforts which were expended in putting this program across.

After a brief historical review of residential care of the mentally retarded, Roos (1969) discusses three basic principles underlying the various approaches to designing living spaces in institutions. These principles, which unfortunately are not necessarily compatible with each other are:

- residents should be cared for with maximum safety and efficiency;
- residents should be treated in as "normal" a manner as possible, so that the institution should approximate a home-like environment; and
- institutional environments should be designed to facilitate programming for all residents.

Roos also discusses the following critical questions related to institutional goals: Do institutions primarily serve society, the economy, the family of the retarded, or the retarded themselves? Is it appropriate to program all institutionalized retarded children for community adjustment? Should residents be grouped heterogeneously or homogeneously? What role can parents play? How can institutions be structured, from an administrative standpoint, so as to avoid confusion resulting from "unitized" multi-disciplinary staffing? What are appropriate sources of financial support? Will large institutions survive and in what form?

A special treatment by Rowland and Patterson (1972) looks at the re-conceptualizing of the traditional institutional model to encompass the developmental institution. In this model the institution is seen as a source of educational opportunity rather than a place where therapeutic activities for the severely retarded are provided. Every function is oriented to the needs of the individual. The adoption of this model, it is noted,

would require a major value transformation on the part of the institutional personnel.

Douglass (1971) predicts an upgrading of the caliber of facilities and services within institutions for severely and profoundly retarded persons. He also forecasts that there will be continued efforts to promote alternative living arrangements, small group homes, cottage plans, and improved staff-to-resident ratios.

In a collection of papers edited by Kugel and Wolfensberger (1969), authorities in the field of mental retardation discuss changing patterns in residential services for the mentally retarded. The first section of the text focuses upon the challenge of innovative action, basic facts regarding the current status of residential facilities, personal reactions to current models, and the history and development of institutional models in the United States. The second section of the volume presents conceptualizations of models of adequate service delivery, and in-depth descriptions of already established model programs for the mentally retarded. Various proposals are concerned with new and radical innovations and recommendations for change in service delivery patterns. A theme consistently stressed in the text is the need to include residential services as one component of a continuum of services for the mentally retarded. The collected materials edited by Baumeister and Butterfield (1970) also include many relevant discussions of features of residential facilities which must be examined.

In response to these changes in institutional goals, new standards for residential care have been developed. Both nationally and internationally, consumer groups and professional associations have attempted to improve services for the retarded. The President's Committee on Mental Retardation (1971) reports the formation of a federally funded Council for Accreditation of Mental Retardation Facilities to work with the Joint Commission on the Accreditation of Hospitals and the International League of Societies for the Mentally Handicapped. The Joint Commission has published Standards for Residential Facilities for the Mentally Retarded (1971) which delineates standards for resident living, including relationships with staff, activities, food services, clothing, health, hygiene, grooming, grouping and equipment,

and design of living units. Program areas covered by the Standards are listed in alphabetical order and include: dentistry, education, food and nutrition, library, medicine, nursing, pharmacy, physics, physical and occupational therapy, psychology, recreation, religion, social work, speech pathology and audiology, vocational rehabilitation, and volunteer services. Also included are standards for record-keeping, research, safety and sanitation, and administrative support services.

Similarly, the International League of Societies for the Mentally Handicapped (Residential Care for the Mentally Retarded, 1969) developed basic principles regarding residential care for the retarded. A symposium of representatives from 12 National Member Societies of the League was convened to discuss current trends and achievements in the provision of residential care to the mentally retarded. Endorsing the principle of normalization, the group proposed a developmental approach to care of the retarded and agreed that residential services must be viewed as one point along the continuum of available services. The group related the issues of administration, size, and physical environment to residential service delivery, and made recommendations for individual evaluation and programming. They also discussed two models which embody these principles: the decentralized institution and the simplified community-like institution.

The Council for Accreditation of Facilities for the Mentally Retarded has developed standards for residential facilities (Crosby, 1972). Education standards are offered for the guidance and instruction of educational providers and for use in a national voluntary accreditation program aimed at improving all services for the retarded. Perhaps the most significant provisions of these standards are:

- educational services should be offered all residents, regardless of age, level of retardation, or other disabilities;
- educational programming begins at birth;
- institutions should provide educational programs at least equal in quality to those provided by the public schools;
- residents should attend public school programs whenever possible; and

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- educational programs operated by a residential facility should not be isolated from the community or from the mainstream of educational endeavor.

In Residential Services for the Mentally Retarded (1970) there are papers dealing not only with standards of residential care but also with the conditions under which such care is appropriate, the legal rights of the individual, needed services, regional and community resources, features of residential care for the mentally retarded in England, and the need to evaluate different forms of care.

To analyze institutional differences in the United States, Silverstein (1967) collected data on 13 variables from 130 public institutions listed in the Directory of Residential Facilities for the Mentally Retarded (Milligan and Nisonger, 1965; Nisonger, 1968). Analysis of the 13 variables produced four factors: adequacy of cottage and medical personnel; adequacy of teachers, psychologists, and social workers; institutional age, overcrowding; and resident competence. While these findings are neither new nor unexpected, they are worth noting here because of the clarity with which these four factors emerge as critical across a wide variety of institutional settings.

Scholl (1968), Principal Consultant for a grant to the National Accreditation Council by the Social and Rehabilitation Service, has prepared a detailed volume designed to enable individual providers to evaluate themselves. The contents include a manual of procedures and the underlying philosophy and objectives. The individual evaluation sections cover the entire gamut of subjects of concern in the operation of a residential facility, from general curriculum planning, which is broken down into specific subject areas, to health and safety and administrative/staffing issues.

Goal setting and establishment of standards have had a perceptible effect on institutional change. Plans for reorganizing the Fernald School (Dybwad, 1969), initiated in the middle 50's, are currently being implemented. For example, there are several behavior modification programs, and children who have attained a requisite level of self-care skills are being bussed to the regular schools in their community of residence whenever possible.

Similarly, changes in goals have been translated into action at the Miami Sunland Training Center, a large residential institution for the mentally retarded. Cortazzo et al. (1972) describe the Center's transformation from a traditional department and profession centered institution to a divisional, resident and program-centered model. The Center has developed a specialized unit for each of four major program functions:

- vocational rehabilitation,
- education and training,
- independent living, and
- development and training.

As part of the new approach, every resident is provided with a meaningful, comprehensive program individually designed and based on team prescriptions. These are carried out by assigned team members, with frequent evaluation of performance objectives. Parents of residents are often involved in group and individual meetings.

#### 1.6 Guides to Providers

At the outset it should be noted that no listings focus specifically on providers of services to the profoundly and severely mentally retarded. There are, however, many references which are concerned with the total mentally retarded population. Usually such directories will specify the level of retardation and other accompanying handicaps which can be accommodated at a specific site.

Basically, provider information is available through three major sources. First, agencies in several states provide information on services available to their mentally handicapped population. For example, listings and/or directories are available for Washington, D.C. (Comprehensive Mental Retardation Plan, 1969); Georgia (Directory of Services for the Mentally Retarded, 1966); New Jersey (New Jersey Comprehensive Plan to Combat Mental Retardation, 1966); and West Virginia (A Plan Called Promise, 1966). All but the Georgia plan present the total statewide program for dealing with mental retardation, of which information on available services is only part.

Secondly, the results of several nationwide surveys provide another information resource. Thus, the findings of a survey of state vocational rehabilitation agencies include, for each state, a detailed description of an "exemplary" program as well as a list of programs with which the vocational rehabilitation agencies are concerned (Services to the Mentally Retarded: Vocational Rehabilitation Involvement, 1973). Segal (1971) reports on a survey of state agencies and provides an interesting analysis of trends and patterns in services delivered to mentally retarded people. Scheerenberger's (1965) report on an AAMD survey of 138 state institutions includes valuable information on a number of topics, such as distributions of the client populations by age and level of severity of handicap. State and national trend data on public institutions is provided by Starr and Warsack (1968).

Directories constitute the third major source of provider information. One of these is published by AAMD and lists all residential public and private facilities for the retarded (Nisonger, 1968). Another valuable resource is the Directory of State and Local Resources for the Mentally Retarded (1969), published by the U.S. Department of Health, Education, and Welfare. In addition to listing residential and special facilities and clinical programs for the mentally retarded, this reference provides useful information on the coordinating agencies in each of the 50 states and the U.S. territories, state-administered programs, and non-government state resources. The Mental Retardation Source Book (1972), also published by the U.S. Department of Health, Education, and Welfare, provides statistical data from all of the mental retardation programs administered by various agencies of the federal government. The first section is devoted to a statistical demographic description of the mentally retarded population in public and private residential facilities including state mental hospitals; the second section reports data on day care facilities, clinics, and psychiatric and educational services; the third section is devoted to data on clients served by the Social Security Administration rehabilitation program, and the public assistance program.

A third HEW publication (Mental Retardation Programs of the Department of Health, Education, and Welfare, 1972) presents the Department's programs for the mentally retarded, organized according to the following categories:

preventive services, basic and supportive services, research, income-maintenance, personnel training, and construction. Reports of eight agencies (the Office of Child Development, Office of Education, Health Services and Mental Health Administration, National Institutes of Health, Social and Rehabilitation Service, Social Security Administration, Food and Drug Administration, and Surplus Property Program) provide program descriptions and discuss objectives, activities, history, publications, and economic impact. The financial policies are also covered, and information is provided on the amount of funds for mental retardation programs available from the Department.

### 1.7 Bibliographies

A number of bibliographies and collections of relevant materials have been referenced in the preceding text. There are also some very useful sources of information on mental retardation in general, but which focus on the severely and profoundly retarded. Bialac (1970), for example, has compiled a wide selection of materials covering community programs, conditioning, education, institutional services, residential programs, and techniques for developing the language, speech, hearing, and mental processes of profoundly and severely retarded populations. Evaluation and programs for parents and families are included, but literature which focuses on medical issues has been specifically excluded.

The 1973 Publications List of the National Association for Retarded Children references and describes approximately 90 publications of that organization. However, the level of retardation is not indicated. Most likely the materials are not limited to treatments of the severely and profoundly retarded. Another general collection, A Selected Bibliography on the Mentally Handicapped (1970), prepared by the Michigan State Department of Education, also includes materials on the educable and trainable mentally retarded. An earlier review of world literature on mental retardation (Heber, 1963) is obtainable from the U.S. Government Printing Office.

There are several bibliographies which provide materials on Down's syndrome or mongolism. These include Gelhart (1966), Stedman and Olley (1969), and an annotated bibliography on Mongolism (1971) which is part of the Exceptional Child Bibliography Series.

A different type of special bibliography is the one by Gardner and Selinger (1971). Over 850 references to research in the field of mental retardation are listed. Of these, at least 50% appeared in journals dealing with mental retardation. Although there was a dramatic increase in the number of articles published in the 50's, a leveling off occurred in the mid-sixties, with a steadily growing emphasis on studies applying behavior modification procedures.

#### 1.8 Future Directions

In many of the articles discussed earlier in this paper there have been references to innovations and trends for change in the care and habilitation of the retarded, with special emphasis on those in the most severely and profoundly retarded categories. Although great strides have been taken in the development of techniques for habilitating the severely mentally retarded, recent accounts of living conditions in residential institutions in the United States (Blatt, 1972) bring a shocking awareness of the distance still to go before the goal of humane and appropriate treatments for all disturbed children and youth has been attained.

With some chagrin it must be acknowledged that the Scandinavian countries continue to be the leaders in advocating humane provisions for the severely mentally retarded (Humphrey, 1968; Clark and Clark, 1970). Denmark is well ahead in developing programs for care and training, having passed legislation in 1959 which made the education of all retarded children between the ages of 7 and 21 mandatory. In Sweden, where a registry of the number and needs of disabled persons has been maintained for almost 100 years, programs stress the importance of separating retarded children by level of functioning, type of illness, and age, even to the inclusion of separate wards for infants. In both Denmark and Sweden comprehensive, tuition-free high school training programs have been designed to train specialized child care workers.

With reference to future directions in this country, Wolfensberger (1969) makes 20 predictions concerning areas of change in residential services for the mentally handicapped. He anticipates that many of the functions of the traditional institution will be assumed by other agencies such as work-

training centers, and that most residents will be integrated to some extent into community life. The new facilities will be oriented toward child development, will emphasize pre-vocational education, and will provide sheltered living arrangements within a community milieu.

In another article by Wolfensberger (1972), the principle of normalization is applied to the issue of residential service delivery. Basically, normalization has as its goal the establishment and/or maintenance of behaviors and characteristics which are as culturally normative as possible. Wolfensberger discusses the implications of this principle for smaller, less institution-like residential facilities.

Orzack et al. (1970), Gardner (1970), Swartz et al. (1971), and Jordan (1972) are but a few of the many authors involved in shaping the directions which the provision for resources and services to the severely mentally retarded will be taking in the future. Current technological capabilities such as in videotaping and other media resources offer untapped potential for increasing the effectiveness of educational and training programs. Clearly, more intensive efforts are necessary to facilitate the optimum development of handicapped children and youth. New ideas in architecture and milieu structures also offer many opportunities which have not been fully utilized. And finally, the effectiveness of behavior modification in eliminating undesirable behaviors and establishing desirable ones seems to support the position taken by Throne (1970) in his prediction of a predominantly behavioral approach to mental retardation.

## 2.0 SEVERE EMOTIONAL DISTURBANCE

### 2.1 Problems of Definition and Classification

Of all the areas of handicap, that of emotional disturbance is perhaps the most difficult and elusive to describe objectively, and the determination of cut-off points for levels of disturbance is, to some degree, dependent upon subjective tolerance for unconventional or peculiar behavior. What one individual or culture may consider deviant, another may accept as perhaps idiosyncratic but not psychotic. The child with whom one teacher may be able to establish a viable rapport in the classroom, another teacher may consider so disruptive or unreachable as to demand special handling.

Furthermore, it is extremely difficult to establish meaningful criteria on which to differentiate three levels, the mild, moderate and severe, of emotional disturbances. The recent literature reviewed for this paper offers little assistance on this problem. There are a number of legal or functional definitions which have been offered; for instance Guidelines for Implementation of the Pilot Program for Emotionally Disturbed Children (1971) states that the term "emotionally disturbed children will be construed to include any child whose emotional condition is medically and psychologically determined to be such that he cannot be adequately educated in the regular public school classes without the provision of special services." Functionally defined, they are those children "17 years or younger who evidence inability to relate realistically with the public school program and who are unable to function near capacity mentally, socially, and emotionally." In the compendium of state laws relating to handicapped populations, the range of definitions of the emotionally disturbed is confined to these few simple constructs. Additionally, the stipulation is usually made that the diagnosis must be made by a qualified professional. Since a major source of confusion is the variety of professional orientations which have constructed theories of mental illness, there is a high degree of possibility that disagreement will occur. The "mental health specialist" might not be willing to accept the educator's description of the disturbed child as: ". . . one who violates classroom norms where no other means of explaining this violation is available."

While the specification of criteria for minimal and moderate emotional disturbance is subject to a great deal of ambiguity and baseline instability, these issues are not too relevant for the present review. Judgments of severe emotional disturbance have a high level of interrater reliability, which increases commensurately with the level of severity. This is particularly true of one subset of psychotic behaviors which make up the syndrome now popularly known as autism. The distinction between autism and severe emotional disturbance is one which is, indeed, rather arbitrary, being based primarily on the presence of certain "psychic withdrawal" symptoms (Lacey, 1969). However, because of the wealth of literature which has been generated in this area, autism will be treated in a separate section, directly following this one.

## 2.2 Prevalence Studies

According to statistics cited in the USOE Practicum Handbook (1970), approximately 5% of the children in the United States in need of psychiatric help receive such service. There is a shortage of teachers of the emotionally disturbed, and adolescent wards are expected to increase in population by 70%. The National Institute of Mental Health (Rosen et al., 1968) has collected data which indicate that approximately 473,000 children under 18 years of age received some type of service in 1966. Of these, 400,000 were treated in outpatient clinics, 27,000 in public mental hospitals, 8,400 in private mental hospitals, 28,000 in general hospitals, 2,500 in psychiatric day-night units, and 8,000 in residential treatment centers. Another source (Emotionally Disturbed Children, 1967) cites government figures indicating that 100,000 children in the United States require hospitalization or an environment completely separate from other children. It is also reported that the number of emotionally disturbed children is increasing at a rate 4.5% greater than the normal population growth.

Questionnaires to obtain information on the current status of public school services for emotionally disturbed children were sent to state directors of special education in each of the 50 states and the District of Columbia (Hirshoren et al., 1970; Schultz, 1971). They obtained data on definition, terminology, prevalence, services available, class size and case load, and administrative organization. Estimates were obtained which indicate that .05% to 15% of all children between 5 and 19 years, or 1,200,000 children, are emotionally disturbed. Hirshoren et al. report that Mackay (1969) and Page (1965) cite incidence figures of 2% and 1% respectively.

Individual states and localities have also carried out studies to determine the incidence of emotionally disturbed children and youth, and the facilities available to serve them. One of the most complete of these is reported by Marrone and Anderson (1970). During 1968-69, 11 elementary classes in Montgomery County served 94 disturbed children. Among these were psychotic, severe neurotic, schizophrenic, and autistic children with behavioral and personality disorders. Prior to 1955, Ohio carried out eight major studies concerned with the prevalence of emotional disturbance (Gloss, 1968). The incidence of severely disturbed children was said to range from

4% to 12%. Gloss also includes a description of 20 experimental research and development programs which were in progress in 1968.

### 2.3 Research and Demonstration

Before looking at the type of research which has been receiving the greatest amount of attention during the last 10 years, it should be reiterated that there are two basic conceptual frameworks in which the study of severe emotional disturbance has been cast: behavior modification and psychotherapy. There are other treatment approaches and other issues with which research and demonstration studies have been concerned, but these receive relatively less attention.

2.3.1 Demonstration Programs. As the review of the recent literature seems to indicate, the appropriateness or effectiveness of behavior therapy is no longer being extensively tested in experimental studies. Instead, there are many reports of institutional settings which have adopted these procedures as part of a regular, on-going treatment program. O'Leary and Becker (1967) report the use of behavior modification in an adjustment classroom. The Engineered Classroom, first conceptualized by Hewitt over 10 years ago, has been a regular part of the Santa Monica School System's approach to emotionally disturbed children, and the University of Kansas Behavior Analysis Follow Through Program has been using token reinforcement with disadvantaged children for the past five years. A four-year rehabilitation program based on behavior theory was carried out with 12-17 year old chronic psychotics in a highly structured residential school setting. The rate of discharge was 88%, with only 13% recidivism.

Camarillo State Hospital (Montgomery and McBurney, 1970), Devereux Schools (Saunders and Balano, 1972), and the Children's Treatment Center in Madison, Wisconsin (Browning and Stover, 1971) have incorporated behavior modification as a total treatment approach in their work with emotionally disturbed children and their families.

Evidently the fact that a large proportion of the emotionally disturbed population have at least normal cognitive ability has influenced most of the

workers in this field to direct their efforts at remediating deficiencies in language functioning, as well as the improvement of other types of academic skills. Thus the vast majority of interventions measure success in terms of how quickly children can return to classes with their normal peers. Knoblock and Johnson (1969) present a series of articles each of which is concerned with some aspect of teaching or curriculum as it may affect the academic learning of the emotionally disturbed child. A similar academic orientation is displayed by Meyers et al. (1968), who have prepared an instructional guide for teachers to use with this population.

Also concerned with academic functioning, Kenney et al. (1966) explored the use of an "educational cadre" to function as a diagnostic, teaching, and research resource for emotionally disturbed adolescents in a residential treatment program. The classroom teacher worked with a curriculum specialist, a cognitive psychologist, and a psychiatric clinician. The experimental curriculum employed units in English and history as the media for the development of cognitive processes and language skills. Kenney reported that observations by teachers, comments of other students, and the work products of the disturbed children themselves indicated that the materials and methods facilitated learning, but this was not supported by performance on the language tests.

Whatever the effect of the "educational cadre," it may just as easily have been the product of the reduced child-adult ratio which resulted from the presence of the extra adults in the program. As Weissman (1970) points out, a teacher-child ratio of from 1:6 to 1:10 is recommended along with a program of highly individualized instruction. Weissman also suggests that the physical environment can have an important impact on the adjustment of the disturbed child; it should be flexible, and there should be "silent corners" where children can be separate from each other if they so choose. It is interesting, however, that when auditory input was reduced, in an experiment by Fassler and Sweeney (1971), there was no measurable improvement in performance. All of the 30 seriously disturbed children in the study had been judged educable by school psychologists but exhibited considerable confusion about reality and had severe difficulty in their ability to relate to others.

Another type of classroom manipulation (Bloch, 1971) was explored in a special program designed to foster language comprehension and to stimulate language production in non-verbal children who suffered severe impairment of intellectual and social functioning. In addition to the use of visual aids, songs, and toys as stimuli to encourage verbalization, children were placed in the group situation as soon as possible and saturated with group and individual experiences designed to engage each child at his own developmental level.

Many academically oriented programs use behavior modification procedures. Thus, Pimm and McClure (1967) described an adjustment class in Ottawa, Canada. The class operates within the context of the regular school system, but consists of a maximum of eight neurologically normal, emotionally disturbed children of normal intelligence. Attendance in the class varies from four months to two years, depending on individual needs. The focus of the program is academic and the goal is to bring each child up to his intellectual potential through individual tutoring and reinforcement procedures. As children progress, they are gradually reintegrated into their regular classes.

An educational approach which stresses language development underlines the program at the Forum School in Waldwick, New Jersey (Dubner, 1971). Based on the expectancy of normal behavior and development, children are provided with intensive stimulation, they are taught to listen and respond, to become aware of their own bodies, and to develop perceptual-motor skills.

Other types of therapies have been explored in demonstration programs. Several investigators report the value of art and music therapy with emotionally disturbed patients. Scott (1970), Price et al. (1972), and Wasserman (1972) utilize music in different ways, but all report significant or encouraging effects. Kramer (1972) provides an extensive description of the use of art therapy. The role of the art therapist is considered central to the success of the program, which operated for two years in a psychiatric ward for children.

Although the recent literature is far more heavily weighted with behavior modification studies, the psychodynamic approach cannot be neglected, and

Reisman (1973) provides a recent overview of this theory as it applies to work with children. The most relevant principle of this technique is that the therapist listens and allows the child to express his feelings and beliefs without judgment or censure. In actual practice, many therapists may utilize positive reinforcement, one of the major tools of behavior modification, to bring about the changes they wish to effect.

Szurek et al. (1971) describe the comprehensive inpatient treatment provided by the Langley Porter Neuropsychiatric Institute in San Francisco. Their psychotherapeutically oriented approach is based on the position that severe emotional disturbance in children is the result of trauma incurred through early parent-child interactions, and they therefore emphasize parent involvement in the treatment program. An interdisciplinary team of specialists works with the family in the creation of a therapeutic milieu.

The milieu therapy technique has been adopted in several countries outside of the United States. Osorio (1970) reports such a program in Brazil, and Ziegler (1972) contrasts Norway's emphasis on this type of treatment with the individual psychotherapeutic emphasis he sees as being dominant in the United States. Kahan (1971) describes a residential facility in England for psychotic and severely disturbed children which continues to rely primarily on individual psychotherapy.

The Elmont Project (Donahue, 1968) also utilizes a psychotherapeutic orientation in a community-initiated program which receives support from both the regular school system and the local community. The goal is to allow the child to return to the regular classroom without isolating him from family, peers, and community during the treatment process. Another such program is that of the Child Psychiatric Day Care Unit of the University Hospital of the University of Washington, Seattle (Gritzka et al., 1970). Similarly, the Hillcrest Children's Center in Washington, D.C. (Long, 1969) is a therapeutic elementary school.

Early intervention is an essential feature in the remediation of most handicaps, but it is particularly important in the case of emotional disturbance. Bluth et al. (1971) have listed almost 100 items which include a variety of treatment models in early intervention.

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An excellent illustration of the therapeutic nursery is provided by Furman and Katan (1969). They describe the Hanna Perkins School for emotionally disturbed preschool children, which adopts a psychoanalytic approach. Similarly, Kliman and Stein (1971) report on the Cornerstone Project, in which a psychotherapist works with an emotionally disturbed child in the context of a regular nursery school classroom. The Regional Intervention Project (Ora, 1970; Ora and Reisinger, 1971) exemplifies the use of behavior modification procedures in a preschool program. This demonstration project was carried out with 40 preschool emotionally disturbed children and their parents. In addition to providing a preschool program for those who could not be handled in the nursery for normal children, other features included: placement, support, follow-up and supplementary services, parent participation, and in-service training for staff. The principal method used in evaluating the effectiveness of the intervention was that of behavioral observations within the therapeutic setting. Awareness of change in the children was pointed up dramatically as parents were trained to use the Vineland Scale to assess social and emotional development. One of the basic objectives of this program, which had a strong pre-academic component, was to demonstrate that a coordinated, regional early intervention system would be more economical than institutional care.

If at all possible, help to the emotionally disturbed child and his family is best provided in the home, supplemented with attendance at a clinic after school hours or in a class designed for disturbed children within the school system. However, this solution may not always be desirable. In some cases the precipitating conditions to the disturbed behavior lie within the home environment and it may be necessary for the child and the family to receive separate intervention treatment before they can make progress together. There are several alternatives to either special-class day care on the one hand or institutionalization on the other.

In some programs which offer special day classes for emotionally disturbed children the facility is not within easy access to the family being served and the child may need to be boarded out during the week. Project 750 (Hoffman, 1969 a and b), so called because of the legislative ruling under which it was funded, involved removing children from regular classes and

placing them in special classes designed to maximize their educational potential and relieve emotional difficulties. Hoffman's report was prepared after the eighth year of the program, which by that time had served approximately 2,400 children, of whom 57% were under 16 years of age. Parents of 44% of the children rated them as improved in social adjustment; 39% said their children had improved academically; and 59% indicated improvement in overall adjustment. One of the major problems encountered in the administration of the program was the lack of clarity of Project 750 regulations in identifying the children eligible for placement under this funding. (Other facilities receiving funds through this legislation are listed in Hoffman, 1969 b).

Often there is a situation in which a severely disturbed child needs placement in a residential setting but such treatment is not available. Willner et al. (1972) described an interim service program consisting of an interdisciplinary approach: a welfare agency, an urban board of education, and a mental health facility which provided short-term, in-patient treatment.

Another instance of an interim approach, described by Atkins et al. (1962), is the Eastern Diagnostic and Evaluation Center in Philadelphia. This Center serves as a screening and referral agency for emergency cases, defined as those in which unusual circumstances require some form of immediate action. The outpatient psychiatric services include evaluation by team members of the adaptive interaction and support systems of both the child and his caretaker. During a 13-month period, 42 children identified as emergency problems were seen and 31% of them were judged in need of hospitalization.

Where immediate institutional placement is not possible, another type of service is necessary. Dorenberg (1969) describes a program which provided counseling services to families and children on waiting lists for traditional therapy. The focus of treatment was on strengthening the self-concept of the parent so as to facilitate coping with the disturbed child in the home.

Short-term placements under residential care followed by continuing non-residential treatment have been explored in a number of settings. The

Wisconsin Children's Treatment Center (Kemp, 1971) provides a residential program which involves the family in the treatment process. Of the 34 children, 4 to 13 years old, treated at the time the report was written, none were returned to institutions and all but one, who was placed in a foster home, were still living at home with their families. Similarly, the Children's Re-education Center in Nashville, Tennessee provides six-month placements for children 5 to 13 years old. Children remain at the Center during the week and are sent home on weekends. Problems are approached from educational, behavioral, and economical viewpoints; behavior modification principles are applied within the total environment, both inside and out of the Center. The individual child's curriculum is adapted to his specific needs, although there is also emphasis on group counseling:

More and more residential treatment centers are moving toward a community health model. Mora et al. (1969) report a ten-year program at the Astor Home for Children. It was marked by an increase in the ratio of professional to child care staff, provision of intensive psychotherapy for each child by members of three orthopsychiatric disciplines, an increased focus on neurological and psychopharmacological treatment, and the development of more concrete techniques in working with families. In particular, attention is given to discharge procedures, group home programs, and foster home programs. A reformulation of the residential center concept to include day education and a day hospital center is also described by D'Amato (1969) who reports the work at the Eastern State School and Hospital in Illinois.

The feasibility of a combined treatment approach, in which 14-17 year old emotionally disturbed boys were given non-residential vocational training while living in residential centers, foster homes, or in group care, was demonstrated by Gellman (1969).

While the most recent change in services to emotionally disturbed children and youth has been in the direction of non-institutional care, this has not always proved to be a happy solution. Chase (1973), for example, notes that in California the consequence of the 1966 Mental Health Services Act has been the closing of many mental hospitals and the return of mentally ill patients into the community, with unfavorable effects on both. In spite

of this opinion, it is dubious that residential care will completely disappear as the major type of provision for the emotionally disturbed for some time to come. Easson (1969), for example, takes the position that there are certain types of adolescent behaviors which indicate the need for hospital treatment. These children require various facets of residential living, such as psychotherapy, medication, and continued diagnosis.

A number of investigators have been studying new ways of working within the institutional context. Mayer and Blum (1971) present a collection of ten papers dealing with various aspects of residential treatment for emotionally disturbed children. Milieu therapy, special education, psychotherapy, and group living are discussed, as well as the role of the child care worker and the volunteer.

2.3.2 Research Studies. The effect of intensive therapy and casework services given to 27 children in foster homes was compared with a similar group of emotionally disturbed children also placed in foster homes but without any special intervention (DeFries et al., 1965). Based on the psychiatric interviews at both the beginning and the termination of the three-year therapy program, 13 experimental and eight control children showed improvement, five experimental and nine control children showed no change, while the condition of eight experimental and nine control children was aggravated. The authors conclude that since their intensive therapeutic effort did not produce significant results, institutional care should take precedence over foster homes.

It is difficult to see how this conclusion was reached, since both the experimental and control groups were in foster homes and no comparisons were made with an institutionalized population. Perhaps they felt that if all their best efforts had failed, there was just no hope for these children. There is no doubt that this is very difficult and often unrewarding work, but a more optimistic note is struck by Ambinder and Falik (1966) who report a foster home program which successfully retained an emotionally disturbed boy in school through several semesters.

The use of small group situations was the basic ingredient in a study with emotionally handicapped elementary school students with normal intel-

ligence and no neurological defects (Miller, 1967). The experimental groups demonstrated significant increment in academic achievement.

A special type of group method called "sociotherapy" was developed by Kok (1972). This integrated multi-disciplinary technique consists of a high degree of structure in group play therapy for the treatment of the "structopathic," emotionally disturbed, hyperkinetic child. Structured, formal lessons in an experimental speech and language program were reported to be less effective than sessions which included at least some play activities (Rubin et al., 1967); but these judgments were not substantiated by statistical tests.

The relationship between specific reading disabilities and emotional disorders was studied by Wilderson (1967). Factor analysis indicated that there were four psychiatric and seven reading deficiency components. These were shown by correlation techniques to be related in the following manner: schizoid-withdrawal and memory; character disorder and intellectual maturity; character disorder and hyperactive style; borderline psychosis and visual efficiency; and somatic complaints and visual inefficiency.

Another type of question which has been explored in a semi-research context is concerned with the most advantageous environment for the disturbed child. Carleton (1967) compared three delivery systems: the day school program, a homebound program for children with problems too severe for the day care program, and an itinerant teacher program for students enrolled in regular classes but who require special work in small groups. If the project is evaluated in terms of the increased demands for admission into the program, then this was indeed a success since the enrollment went from seven in 1965 to ninety in 1968. All children returned to their regular classrooms, but their subsequent ability to function in that setting was not always adequate. No comparative assessment of the three methods used was available.

The COVERT School project (Klein et al., 1967) was also designed to evaluate alternative educational approaches for emotionally disturbed children. Six procedures for meeting the needs of an estimated 3% to 14% of the school population exhibiting emotional disturbance were used: a residential

school, a day school, special class programs, a group-tutorial approach, a support teacher for children in regular classes, and recreational therapy. Evaluative records (e.g., attendance, number of sessions, number of parent contacts, total group changes, etc.) were kept, but no quantified statistical analyses were reported.

Finally, Greenberg and Meyer (1974) explored the use of the group home, a single family dwelling with four to five children living with a couple, as a transitional home for emotionally disturbed children who had been discharged from residential care/treatment but were not yet ready to return to their own families. The experience was reported to have proved successful for 41 of the 59 children.

2.3.3 Research with Emotionally Disturbed-Mentally Retarded Children and Youth. In dealing with the problem of mentally retarded and emotionally disturbed children and youth, it is appropriate to begin with a discussion of the difficulty of separating the descriptions of these two handicapping conditions. There is a strong case for developing a common set of concepts with which to organize and classify the phenomena which characterize both of these handicaps.

Many specialists working in the field of mental retardation are extremely unhappy with the classification of levels of retardation on the basis of a psychometric measure of performance on intelligence tests. However, the periodic efforts to introduce multifaceted criteria which would give some weight to personality variables have been consistently rejected. The systems currently in use are described primarily in terms of cognition whereas emotional disturbance is defined in terms of personality variables. This tends to foster false dichotomies, and there is a need to recognize that retarded children are also influenced by social-emotional and attitudinal-motivational variables (Milgram, 1972).

A further complication is that many of the behavioral symptoms of mental retardation are similar to those which are characteristic of autism, and many autistic children are also often said to be retarded. In many areas of the country the primary diagnosis is dependent upon what type of services are most readily available; since there are usually more facilities

for the retarded, autistic children are often classified as mentally retarded with emotional disturbance as a secondary handicap, and little attention is paid to whether the autistic child, if reached, would have the capacity for normal mental functioning.

The literature review yielded only a few studies with mentally retarded children who were also characterized as emotionally disturbed. Of these, four are concerned with the application of behavior modification techniques to eliminate stereotypic and hyperactive behaviors. In a study by Edwards and Lilly (1966), operant conditioning was used to improve the mealtime behavior of 26 assaultive female patients with IQ's of 5 to 25, maintained in a closed ward at Fairview State Hospital in California. All subjects were ambulatory and hyperactive with little verbal language; all but three were self-feeders. Conditioning included changing mealtime procedures by inviting groups of patients into the dining room instead of admitting only a few at a time. Satisfaction of hunger was used as the initial motivation and food as the reinforcer. Mealtime behavior improved significantly, with fewer supervisory employees needed. However, the improved manners at mealtime did not transfer to more acceptable behavior in other daily activities. Twardosz and Sajwaj (1972) used a prompting and reinforcement procedure to train a severely retarded hyperactive preschool boy to sit still. Sitting was significantly increased over the course of the experiment; however, an unexpected side-effect was an increased ability of this child to use toys and to remain close to other children. In addition, the child decreased posturing mannerisms while retaining normal walking behaviors. The results of this study demonstrate that operant procedures can be designed to address several behaviors simultaneously, and thus to maximize the teacher's effectiveness.

Two experiments were conducted by Mulhern and Baumeister (1967) to determine the effectiveness of reinforcement procedures in modifying stereotypic rocking behaviors in two untestable, non-verbal retarded males. Operant conditioning techniques were used to eliminate rocking and to produce sitting-still behaviors. Aversive noise was associated with movement and reinforcing lights and candy were contingent upon sitting still. The overall

Effect of the treatment was a reliable reduction in the rate of stereotypic activity for each subject.

In a controlled experiment using 94 pairs of retarded children, where one of each pair had severe hyperactivity problems and the other did not, the hyperactive group was found to have a notably higher incidence of central nervous system damage or dysfunction, residual speech defects, and convulsive seizures (Jenkins and Stein, 1971). Hyperactive children in the study had lower social quotients and fewer were completely toilet trained than in the non-hyperactive group. Additionally, the hyperactive group were more destructive, withdrawn, assaultive, overanxious, and fearful. Evidently severe hyperactivity unfavorably affects the prognosis for behavioral adjustment of retarded children. This poor prognosis is exacerbated by the fact that disturbed retarded children are frequently rejected from the community and placed in institutional settings where their emotional disorders go untreated, although there are effective methods of treating many emotional problems (Menolascino, 1972).

Overactive, profoundly retarded children were compared to a control group of normally active children with the same degree of retardation (Tizard, 1968). Observations made during the free play period indicated that the overactive children moved about significantly more but were not rebuked more often nor did they receive more attention from their teachers. They were not more aggressive than the control children, but made fewer friendly contacts. The classical hyperkinetic syndrome was not observed, but there was a very wide range of variation in personality. There is some evidence that these children had suffered a different type of brain damage than found in the control group.

#### 2.4 Measurement

Because there has been no analog to the intelligence test to use as an objective basis for classifying emotional disturbance, a great deal of effort has gone into the development of screening instruments. Only a few of the relevant studies, those which have appeared in the most recent literature are included here.

Saunders (1972) reports the development of a teacher-administered procedure for screening, identifying, and diagnosing (SID) emotionally disturbed children in rural elementary schools. It can be administered by the classroom teacher under the supervision of a trained SID coordinator. The procedure uses two instruments, the Lambert and Bower Behavior Rating of Pupils and the Burke Behavior Rating Scales. These provide diagnostic evaluation and prescriptions for specific educational programming for each child.

In order to ascertain the efficacy of screening procedures for emotionally disturbed children in a two-county rural area in East Central Illinois (Schultz et al., 1972), the Lambert and Bower screening instrument was used, together with a behavior problem checklist developed by Quay and Peterson. All the third and fourth grade children were observed and used in investigating the validity of the procedure. No effect of bias resulting from interpersonal compatibility was demonstrated, but there was a low order relationship between children identified as potentially disturbed and the frequency of problem behaviors.

A rigorous instrument development study was carried out by Fink (1971) at Indiana University. In response to the need for more precise analyses of the complex educational and psychological processes in special classes for the emotionally disturbed, Fink describes an interaction analysis system for rating teachers and students within several categories of behaviors. Reliability ratings of .85 were reported after the system was tested in 15 classes for emotionally disturbed children.

Perhaps the most comprehensive and well documented effort at scaling emotionally disturbed behavior, particularly of younger children, is that of Kohn and Rosman (1973). Their approach hypothesizes a two-factor bimodal model of emotional disturbance. Factor 1 consists of interest-participation versus apathy-withdrawal and Factor 2 cooperation-compliance versus anger-defiance. There are two separate scales: a problem checklist and a competence scale. The problem checklist consists primarily of items which reflect deviancy, such as temper tantrums and other types of aggression, acting-out, or withdrawal, passivity, or timidity. The observer enters a rating in terms of whether the behavior is very typical, somewhat typical or

not at all typical of the particular child. The items are coded so that two separate scores are obtained. A high score on the clinging, fearful, repressed items indicates the extreme pole of Factor 1, which is apathy-withdrawal; a high score on the destructive, fighting, and hostile items indicates the anger-defiance extreme of Factor 2. It is the checklist which relates most particularly to the emotionally disturbed child. The Competence Scale is used primarily to determine the level of functioning in child-teacher, child-child, self-care, child activities, and transitional areas. A low score, or the relatively infrequent occurrence of the negative behaviors, would infer behavior at the positive pole for each of the two factors.

Over several years of investigation, 1,425 children between the ages of three and seven years were observed in a variety of treatment settings, and a great deal of refinement of the scales was carried out. The final factor dimensions have been effective in differentiating disturbed from normal children. Specific findings made it possible to characterize the disturbed group as including significantly more males than females and significantly fewer children from intact homes. It is interesting to note that girls show predominantly Factor 1 pathology (apathy-withdrawal), but only those who showed Factor 2 pathology (anger-defiance) were likely to be referred for treatment. With boys the frequency of both types of pathology was more nearly equal.

There is a noticeable lack of evaluative assessments in any of the reports reviewed here, and even those which claim to be experimental studies are extremely weak or non-existent analytical designs. An "experiment in environmental adaptation" was reported by Flint (1966). Staff members rated the 83 children at the McNeal Infants Home on "security scales appropriate to the child's age" and found that children gradually "became competent in self-help skills." After 15 months, 44 children had been returned to their homes or placed in foster homes. Five case histories were also reported. Bilsky (1970) reports the attempt to evaluate a teacher rating and observation technique used in a preschool program. Nine boys and two girls were the basis of the statement that the observation procedure was useful for evaluating similar programs.

Closed circuit TV technology was used to evaluate a program for emotionally disturbed children in the 6 to 13-year age range (Higginbotham, 1971). Video tape films of many of the school's 200 children were taken so that teachers could observe their own behaviors, and also for public relations and dissemination purposes. However, no analytic plan for using any of the findings were reported.

With the exception of programs which utilize behavior modification techniques and which tend to support the effectiveness of their procedures by experimental analyses, only one objective evaluation of a therapeutic program for emotionally disturbed children was encountered in the literature surveyed for this report. This was an evaluation of An Exemplary Program of Special Education for Handicapped Children (1969) funded under Title III of ESEA. Evaluative criteria were used by both internal and external evaluators. Data include standardized test scores, detailed case studies, and observational techniques and information on comparison groups.

## 2.5 Guides to Providers

A limited number of listings which cite only providers for emotionally disturbed children and youth were reviewed. Among these are:

Garfunkel (1970). Handbook of facilities for emotionally disturbed and socially maladjusted children and adolescents;

Hirshoren et al. (1970). A survey of public school special education programs for emotionally disturbed children;

Hoffman (1969). Resources and referral handbook: Project 750; and

Pappenfort and Kilpatrick (1970). A census of children's residential institutions in the United States, Puerto Rico, and the Virgin Islands, 1966. Volume 4: Institutions for emotionally disturbed children.

## 2.6 Bibliographies

There are several recent references which consist of compendia or collections of articles which deal with various facets of treatment, rehabilitation, and education of emotionally disturbed children. Since 1956, the Children's Bureau Clearinghouse has listed 842 research projects in the area

of emotional disturbance (Research Relating to Emotionally Disturbed Children, 1968), and a Bibliography on Emotionally Disturbed (1970) was published by the Michigan State Department of Education.

A great many studies have demonstrated the effectiveness of behavior modification procedures with emotionally disturbed patients. The Exceptional Child Bibliography Series has collected 81 references to such studies (Behavior Modification, 1971), and Graziano (1971) has edited a collection of 39 papers which demonstrate that behavior therapy is successful in producing desirable behaviors in schizophrenic, autistic, and psychotic children.

Faas (1970) brings together 34 articles concerned with identifying, understanding, and educating emotionally disturbed children within the public school. It is dubious whether severely disturbed children will be encountered in this context. The book by Harshman (1969) deals with the ways school systems serve the emotionally disturbed, including special classes, residential centers, and special curricula and techniques. Shean (1971) has edited a collection of 29 papers which deal with studies on classification, as well as a variety of specific character disorders. Although these are not of particular interest here, the presentation of conflicting theories of neurotic patterns in terms of psychodynamic processes versus operant conditioning provides a useful framework for understanding much of the literature in this area of handicap.

Among the many selective bibliographies compiled under the aegis of the Council for Exceptional Children are three which are specifically concerned with the emotionally disturbed. One entitled Mental Health was published in 1971; Emotionally Disturbed--Programs and Emotionally Disturbed--Research were published in 1972. The latter two represent all the items on these topics listed in the Council's Exceptional Children Information Center as of July, 1972.

Bryson and Hingtgen (1972) have prepared an annotated bibliography on early childhood psychosis which includes writings on infantile autism, childhood schizophrenia, and related disorders. There are 424 entries, among which are books, journal articles, and conference and research reports dating from

1964 through the middle of 1970. For earlier work, these authors recommend the bibliographies of Goldfarb and Dorsen (1956) and Tilton, DeMyer, and Loew (1966).

Finally, Tompkins and Allen (1968) have condensed a series of addresses related to treatment, rehabilitation, and education of severely disturbed children.

## 2.7. Autism

2.7.1 Problems of Definition and Classification. Childhood schizophrenia and autism are terms applied to patterns of observed behavior which vary so extremely from the normal that they are classified as psychotic. Because the etiology of this psychosis is uncertain, the literature on childhood psychosis, which includes both autism and schizophrenia, is replete with confusion as well as with contradictions. Thus the precision of both terms is extremely limited; frequently the same set of behaviors is given different names and different syndromes bear the same name.

The term "autism" first entered the literature of psychopathology in 1942, when Kanner published his now classical article. His criteria for diagnosing the syndrome which he called "early infantile autism" were: extreme self-isolation, impaired communication as demonstrated either by echolalia or muteness, obsessive insistence on the maintenance of sameness, and fascination for objects accompanied by a disinterest in people. For the next 20 years, until the work of Ferster and Lovaas, the study and treatment of autistic children was under the aegis of psychiatrists and psychoanalysts, the etiology of the pathology being tied to psychogenic theory.

A brief history of the clinical recognition of autism is included in Rutter's 1971 introduction to the proceedings of a symposium on this topic. Rutter attributes the difficulties in classification to the variety of disciplines concerned, including pathology, pediatrics, psychotherapy, and psychology. However, after reviewing over 315 references to early childhood psychoses, Hingtgen and Bryson (1972) note that the description of the symptomatology is remarkably similar, in spite of the variety of diagnostic systems used. In a more cynical vein, Despert (1971) remarks that the current

worldwide recognition of the syndrome, which was unnamed and virtually unknown just 30 years ago, reflects not so much increased knowledge as greater confusion.

Tustin (1972) presents a classification system which depends to a great extent on the psychoanalytic formulation. Thus, "abnormal primary autism" is the abnormal prolongation of the normal autism of infancy and occurs as a result of inadequate early nurturance; "encapsulated secondary autism" is said to occur as a "defense against the panic associated with unbearable body separateness;" and "regressive secondary autism" is characterized by a return to infantile behaviors after normal development has occurred. Laretta Bender (see Goldfarb, 1970) does not accept autism as a separate category of mental illness, but her scheme for classifying childhood schizophrenia included a description of children with "autistic or regressive withdrawal," as characterized by developmental arrest, homeostatic response, and inadequate biological regulation. Similarly, O'Gorman (1970) outlines nine diagnostic criteria for the autistic syndrome, which he views as synonymous with schizophrenia. Somewhat vaguely, he describes schizophrenic withdrawal as one of a series of alternative, consecutive, or coexistent mechanisms through which the child seeks to adjust himself to his environment.

Wing (1966) carefully differentiates autism, schizophrenia, and childhood psychosis. He describes autism as a set of functional abnormalities and communication disorders which result from the child's inability to make meaningful patterns out of sensory stimuli. Although Rutter (1970 a and b) conceives of the condition as a disorder of cognition and perception, with impaired social development as a secondary consequence, his criteria for identification are very similar to those of Kanner. They include difficulty in forming human relationships, severely retarded language development, the presence of various ritualistic and compulsive phenomena including a phobic reaction to change, and self-mutilation and hyperactivity. In addition, Wing (1966) notes a high frequency of difficult, premature, and Caesarian births among the population of autistic children.

These findings seem to be related to the etiological theories that have developed regarding autism. Wing, for example, uses the sex distribution

and predominance of difficult births to support his hypothesis that the autistic's "inability to make sense out of sensory stimuli" is in fact the result of a disorder of the central nervous system. Implication of the central nervous system is also explored by Kugelmass (1970), who discusses various neurophysiologic, psychogenic, and biochemical etiological theories underlying autism. Goldfarb (1970) cites a number of earlier studies which attempted to link the presence of autism, or any other childhood psychosis to abnormal parenting. This approach reflects the early linkage to psychoanalytic theory. More recent research has demonstrated that parental psychopathology is not as important a causative factor as had been originally thought. Most of the current work with autistic children adopts an eclectic view, but one in which the behavioral component is predominant.

2.7.2 Prevalence Studies. The demographic and incidence statistics available on children diagnosed as autistic reveal several interesting patterns. Hamblin et al. (1967) report that autism is more common than either blindness or deafness, and that of 500,000 severely emotionally disturbed children in the United States, approximately 10,000 are autistic. Rutter (1970) cites the following:

- about 3 or 4 of every 10,000 children are autistic;
- the condition is approximately 3 or 4 times as frequent in boys as it is in girls;
- children from middle class families are more likely to be autistic than those from less affluent families;
- the intelligence levels of autistic children vary from untestably low to normal or even above normal; and
- there is a great variability in intellectual functioning, especially as it relates to language.

2.7.3 Research and Demonstration. A substantial amount of research has been carried out under the rubrics of both autism and childhood schizophrenia. The Council for Exceptional Children, in the Exceptional Child Bibliography Series, devotes one of its reviews to the subject of Autism (1971). This reference includes 47 items from research reports, journals, conference papers, program guides, and text books concerned with various

aspects of autism. Although Goldfarb (1970) does not elect to treat autism as a separate diagnostic category, he reports a number of experiments and tests, conducted by himself and other scientists, on dimensions related to sensory-perceptual abilities or deficits, and cognitive functioning. The overall findings suggest that while the peripheral sensory intake structures are ordinarily intact in psychotic children, their perceptual response abilities are significantly lower than those of normal children.

These results are similar to those reported by Metz (1967), suggesting that autistic children prefer, and will act to maintain, higher than normal levels of stimulation. On the other hand, Fassler and Bryant (1971) report significant improvement in the attention and performance of autistic children when ear protectors are used to reduce auditory input. Goldfarb (1970) relates this high sensitivity to noise levels to an aberration of sensory dominance and normal hierarchical structuring of sensory perceptions. In the research efforts summarized by Goldfarb, schizophrenic children were found to respond most to light, next to touch, and least to sound. Accordingly, Hermelin and O'Connor (1971) hypothesized that this phenomenon might be a factor in the impaired speech of psychotic children. Hermelin and Frith (1971) report further research on perception, memory, and language which shows that autistic children have difficulty in perceiving the content and structure of meaningful, ordered sequences. Typically, the response pattern is one normally found only in random or unstructured situations.

Much of the research on psychosis in children has been directed at identifying their characteristic traits through comparisons with non-autistic children. In one such study, Wolf et al. (1972) report that the mentally retarded children were superior to the autistic children in communication, vocalization, and expressive speech; they also showed better relationships with adults and a stronger drive for mastery. These results further suggest that fragmentation, compartmentalization, and lack of generalization among areas of functioning are factors specific to the autistic process.

Other research studies involving comparisons of psychotic and mentally retarded children were conducted by Goodwin and Goodwin (1970). They interpret their results as evidence that autistic children are frequently

misdiagnosed as retarded, but in reality they are neither incurable nor ineducable. While the difficulty of administering tests to autistic children renders suspect many assessments of intellectual functioning with this group, Alpern (1967) has demonstrated the viability of psychometric measurement with the Cattell Infant Scale. DesLauriers and Carlson (1969) in a comprehensive discussion written primarily for parents of autistic children, also mention the problems inherent in testing and advise a cautious interpretation of test results. Hutt and Hutt (1969) report a series of studies in which reactions of autistic children are examined in a variety of situations. The first study showed that their behavior became increasingly pathological with increased situational complexity. A second study, comparing social behavior among autistic, brain-damaged, and normal children, demonstrated that autistic children became increasingly withdrawn whereas the brain damaged children in the largest group exhibited aggressive behaviors. The third study involved the exposure of each of these children to a novel toy. The normal and brain-damaged children showed great interest in the new object during the first two or three exposures, while it was not until the third or fourth time that the autistic children saw the toy that they stopped actively avoiding it.

Research on autistic and schizophrenic children is heavily weighted with studies involving the use of behavior modification techniques. Lovaas et al. (1972) report on one experiment in which the Stanford-Binet Intelligence Test and the Vineland Social Maturity Test were used to measure the effects of a behavior therapy program emphasizing language training with 20 autistic children. The treatment was designed to extinguish pathological behaviors through withholding of positive reinforcers or presentation of aversive stimuli, or reinforcement of incompatible behaviors. Another technique was the designing of situations in which the emitting of the desired language behavior would be optimized, thus affording more opportunities for administering rewards. Although some children progressed more than others, all improved to some degree. The children were tested following two years without treatment, and the results showed large differences in retention of the learned behaviors, depending on the post-treatment environment. Finally, reinstatement of therapy was found to re-establish the experimental gains only in institutionalized children.

Using a behavior modification treatment also produced favorable results with a group of 149 schizophrenic children, aged two to five years (DeMyer, 1967). In an experimental program reported by Ward (1970) both autistic and schizophrenic children were successfully trained using an adaptation of DesLaurier's "structural therapy" approach.

Smolev (1971) reviews the research that has been conducted in the application of operant techniques especially in the reduction of self-injurious behavior. He cites a number of case studies in which these techniques have been particularly successful.

Brown et al. (1969) describe a six-month program of reinforcement therapy which dramatically reduced the occurrence of negativistic behavior, such as tantrums, and increased the frequency of relevant, functional behaviors in a six-year-old autistic boy. Hill (1967) describes a program in which the self-stimulatory behaviors of ten schizophrenic and autistic children were reduced, and appropriate behaviors increased, through reinforcement therapy. The parents were also trained to apply the reinforcement procedures in the child's day-to-day life. A program described by Goldstein and Lanyon (1971) used parent-clinicians in the language training of an autistic child. The parents were first taught the modeling-reinforcement procedures, and then conducted 125 therapy sessions of 45 minutes duration with their ten-year-old autistic son. Following this treatment, definite improvements were noted in the child's language skills and in his ability to communicate both within and outside the home.

The application of behavioral techniques for language training is described in a case study prepared by Sulzbacher and Costello (1970). The subject, a six-year-old child with grossly deviant behavior, received five 20-minute sessions each week. Following three-and-one-half years of treatment, the child scored at the fourth grade level and demonstrated essentially normal language performance. Marshall and Hengrenes (1970) describe a communication therapy program for autistic retarded children. The individualized reinforcement techniques used in this approach are illustrated along with results achieved in a series of four case studies. Wolf and Guttenberg (1967) describe a day care center program aimed at developing language and communication in two-and-one-half to five-year-old autistic

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children. The underlying theory governing the program was that the children would respond to intensive communication stimulation. The program resulted in the meaningful use of words by most of the children. Similarly, Stark et al. (1968) documented the step-by-step progress in verbal behavior achieved by a five-year-old boy who was apparently unresponsive to all types of environmental stimuli. The child was trained in a five-month therapy program.

Hartung (1970) places major emphasis on the importance of establishing verbal behavior in non-speaking autistic children. To this end, he presents an excellent review of the theoretical bases and procedures of verbal conditioning, and a detailed description of the stages and trends in conditioning verbal repertoires. Finally, he stresses the importance of the role played by imitation in the learning of functional speech. Graziano (1970) describes a rather unique program based on the application of behavior modification in a group setting. The participants were several severely autistic children who had resisted all previous treatment approaches. After four years of therapy, the children were found to interact purposefully with one another in a class and in social situations for four-hour periods each day. The successful training and use of nonprofessionals as therapists represents another unique feature of this project.

A group approach to therapy was also the basis for a nursery school program described by Auerbach (1965). Autistic children were first treated individually, then gradually integrated into regular nursery school classes. The program includes counseling and other services for the parents as well as follow-up services. Frequently it takes up to two years before the children can participate successfully in regular classes, and those who are unable to do so are referred to other treatment centers. A behavior modification program aimed at integration of children in the regular classroom is reported by Hamblin et al. (1967) to have achieved its goals in a much shorter time frame. They hypothesize that the syndrome is a "set of habitual response patterns maintained and intensified by exchanges which are inadvertently structured by others in the child's environment." A seven-stage program, based on the application of "exchange therapy," is recommended in order to reverse or replace these pathological habit patterns. The process relies heavily on standard reinforcement procedures, with the

parents trained to serve as assistant therapists at home and in the classroom. "Exchange therapy" is purported to be so successful that children can be placed in a classroom situation within six to eight months.

The final report of a three-year project (Ferster, 1968) includes a detailed account of a treatment and education program in which techniques of both experimental psychology and operant conditioning were used with autistic children. Ferster's report describes the project and the children and provides information on the materials and procedures used and the staff training program. The application of structural therapy and the role of reinforcement within this approach are described by Handford and Ward (1969).

In addition to these applications of behavior modification techniques, the literature also contains descriptions of programs based on other therapeutic approaches. The model described by Schopler and Reichler (1968) employs a more psychodynamic orientation. In a clinical setting, parents observe therapists and serve as co-therapists. Later, the home component of the program gives parents the responsibility for conducting and recording daily sessions with their autistic child.

Several investigators have studied the effect of modifying the environment in which the autistic child is treated. Goldfarb et al. (1969), also within a psychodynamic context, discuss a corrective socialization approach in which the child's environment is modified so as to provide an opportunity to close "maturational gaps." Another type of environmental manipulation is described by Richer and Nicoll (1971). Here a playroom was designed to reduce frustration, arousal, and flight behaviors, and to reward approach and social interactions. The environmental control employed by Goodwin and Goodwin (1970) was even more rigorous. They used the Edison Responsive Environment, which consists of a cubicle containing an electric typewriter, a projector, and a programming device that directs or responds to the child's inputs, for both therapeutic and diagnostic purposes. Evidently the removal of the social element of the teacher makes this a more viable learning situation for children who experience difficulty in interpersonal relationships.

Elgar and Wing (1969) describe in detail the approaches used at the Society School for Autistic Children at Ealing, England. Distinctions are

made in their treatment among methods to reduce behavior problems, provide formal academic instruction, inculcate practical skills, and foster appropriate emotional responses and social integration.

The objectives, procedures, and problems underlying an educational program for autistic children are presented in detail in two articles by Rutter (1970 a and b). Citing the evidence of many studies, Rutter believes that there can be no doubt but that many autistic children are educable, and that research efforts need to be designed to identify which of the many educational programs described in the research are the most effective. He cites three basic principles: 1) The teacher must gain the child's attention and trust and then provide activities in which he is interested. At first this may mean accepting the child's obsessive rituals and pre-occupations, but soon the range of activities can be extended and replaced with more varied interests. 2) To begin with there must be a one-to-one relationship, gradually leading to small groups where the child can still receive ample individual attention and supervision. 3) The classroom environment must be as simple as possible, and the program extremely structured, with a very precise timetable.

A major point of disagreement between the psychodynamic and behavioral approaches is epitomized in the second sentence under point 1) above. That is, the behavioral therapist will not tolerate the deviant behaviors and uses shock and any other means at his command to eliminate them. It is interesting that Rutter, in a later article (Rutter and Sussenwein, 1971), includes behavior modification techniques in his comprehensive plan for the treatment of preschool disturbed children.

### 3.0 SEVERELY HANDICAPPED DEAF-BLIND

#### 3.1 Problems of Definition and Classification

Although deafness and blindness are in point of fact two separate disabilities, the presence of one or the other alone, without any other handicap, is not considered a sufficiently severe condition of handicap to be included in this review. A legally deaf-blind person who has learned to function in our society might not be considered "severely handicapped" for

the purposes of this study. But what are the levels of impairment of each individual sensory handicap that, combined, would identify a person as "severely handicapped"? If someone is totally blind or totally deaf, what degree of impairment of the other sensory modality is required before that person's handicap is considered "severe"?

As with the other handicapping conditions, lack of definitional agreement is a major factor contributing to the absence of reliable demographic data. However, attempts at defining deaf-blind persons have apparently been much more successful and produced a good deal less controversy than attempts at defining mental retardation or emotional disturbance. Salmon (1970) cites the definition adopted by the Anne Sullivan Macy Service for establishing eligibility as follows:

The term deaf has been defined to mean inability to understand connected discourse through the ear, even with amplification. The definition of blindness is the generally accepted "legal" definition: central visual acuity of 20/200 if there is a field defect in which the peripheral field has been contracted to such an extent that the widest diameter of visual field subtends an angular distance no greater than 20 degrees.

This definition is considerably less flexible than that which was adopted in 1969 by the United States DHEW Department of Education, Centers and Services for Deaf-Blind Children:

The term "deaf-blind child" means a child who has both auditory and visual impairments, the combination of which causes such severe communication and other developmental and educational problems that he cannot properly be accommodated in Special Education programs either for the hearing handicapped child or the visually handicapped child.

Presumably it would be possible to obtain an objective, physical measure of visual and auditory functioning. These two indices could then be used to set up a matrix such that various levels of disability in each modality are summed to determine the degree of severity of the combined handicaps. Such a precise method for establishing severity does not exist, but this need not interfere with the provision of services.

Since mental retardation is often an artifact of the deficiency in sensory input, the real problem is that unless the deaf-blind child's hearing loss is diagnosed and measured, he may be inaccurately classified as either mentally retarded and/or emotionally disturbed. The misdiagnosis of retardation in deaf children is especially serious because hearing loss is more prevalent in mentally ill and mentally retarded populations. Vernon and Kilcullen (1972) found one-fourth of the deaf in-patients at the New York Psychiatric Institute incorrectly diagnosed as retarded. Three major causes of misdiagnosis include: the use of inappropriate tests of mental ability, the presence of other handicaps in the deaf which mimic retardation or confuse diagnosis, and the failure to identify as deaf those patients with only minimal residual hearing.

There is also a semantic basis for the difficulty encountered in classifying the multiply handicapped deaf population. Curtis and Donlon (1969) reported that the terminology used by professional diagnosticians to describe the child and his life situation consisted of 1646 different terms, with no term ever occurring more than four times. This kind of descriptive confusion is reflected in the literature. There are many accounts of deaf-blind persons housed in back wards of mental hospitals and institutions for the mentally retarded or aging, not identified as deaf-blind or treated as such. Non-retarded deaf children have frequently been placed in public school classes for the mentally retarded.

Not all diagnoses of concomitant handicaps are spurious. It is true that many of the deaf-blind are also mentally retarded and/or emotionally disturbed and it is difficult to establish which is the primary problem. The guidelines of the AAMD specifically state that where retardation is present it should be the primary diagnosis, although it may be accompanied by a more severe level of disability in another area, for example, moderate retardation with total blindness or deafness. The classification of retardation would take precedence.

A profile of the multiply handicapped deaf person was constructed by Bolton (1972), based on observations in a rehabilitation center. The detailed profile characterized the syndrome as a composite of severely limited communication skills, emotional immaturity, low academic achievement,

secondary disabilities, and poor vocational preparation. Robbins and Stenquist (1967), in a study of children with a prenatal history of maternal rubella, include retarded mental development, inappropriate classroom behavior, protosymbolic behavior, and light gazing and other obsessive traits as identifying characteristics.

At Parsons State Hospital and Training Center in Kansas, data were collected on 638 mentally retarded children between 6 and 22 years of age (Lloyd and Reid, 1967). Pure tone audiograms could not be obtained from 156 children who were classified as "difficult to test." Of the 482 tested, 136 or over 28% could be considered hearing impaired. The additional finding that the more profoundly retarded seem to have greater hearing loss throws some doubt as to the validity of the study since Rosenstein et al. (1972) have demonstrated that pure tone audiometry is inappropriate with deaf mentally retarded children.

Vernon (1969) also studied multiply handicapped deaf children and cautioned that the behaviors previously attributed to the condition of being deaf may be an interaction of deafness with other central nervous system pathology. Prematurity, brain damage, Rh factor, and rubella were identified as causally implicated in many of the major types of physical and psychological anomalies in deaf children. All of these are associated with disturbances in the normal development of brain functioning.

### 3.2 Prevalence Studies

A census survey conducted by the American Foundation for the Blind in 1966-67 resulted in a register of 777 children with vision and hearing impairments (Wagner, 1970). These children were receiving services in deaf-blind programs, other educational programs, at home, or in institutions for the mentally handicapped. Another census-type study carried out in 1969 (Hammer, 1970) in Arkansas, Louisiana, Oklahoma, and Texas canvassed 279 teachers, 85 United Fund agencies, 12 caseworkers, 20 education service centers, and 10 parents. From their responses Hammer identified 454 deaf-blind children and adults, of whom 22 were in residential schools for the blind, 142 in residential schools for the mentally retarded (although these may or may not have had the additional handicap of retardation), 12 in day school, and 312 at home. No services for persons kept at home were reported.

As a result of a statewide survey to determine the parameters of the problem of deaf-blindness in Michigan (Harris, 1972), 52 deaf-blind persons, 0-25 years of age, were identified as being in need of special education services. This number represents an incidence rate of 12 per million for this age group. In addition, there were five deaf-blind persons with other serious handicaps.

One of the first surveys conducted by the Deaf-Blind Regional Centers (Dantona, 1970) identified an estimated 2,400 deaf-blind children in need of services. However, the Bureau of Education for the Handicapped reported in 1973 that over 5,000 deaf-blind children had been located.

The blind and/or deaf child often suffers from concomitant disabilities. In a survey carried out by Graham (1967), it was found that over half of the handicapped population sampled had two or more disabilities, including visual impairments, hearing impairments, speech problems, brain damage, cerebral palsy, and emotional problems. About the same time, Wolf (1967) polled the chief administrators of 48 residential schools for the blind. According to their estimates, 25% of the total population of almost 6,700 children were mentally retarded with an average of 3.18 disabilities per child.

The San Francisco Hearing and Speech Center (Lance, 1967) indicated that 984 deaf children under the age of 15 had at least one other major handicapping condition. When this estimate is corrected to include the many unreported cases, and also to take into consideration the fact that over 1,000 children affected by the rubella epidemic of 1964-65 were at that time under six years of age, it can be seen that the figure cited was a gross underestimate.

Lowenfeld (1968) found that of 940 multiply handicapped blind and 240 deaf-blind children under 21 years of age receiving services from the California State Department of Education, Division of Special Schools and Services, 32% were described as severely mentally retarded, 10% as moderate and 4% mild. No data were reported on the remainder of the sample.

Based on information in the cumulative record folders of 1,632 pupils in six schools for the deaf, Anderson and Stevens (1969a) estimated that

40% of the multiply handicapped deaf were mentally retarded. Power and Quigley (1971) cite figures which indicate that 30% of deaf children have one or more additional disabilities. This is considerably more conservative than Leach (1971), who surveyed 258 organizations for the multiply handicapped visually impaired child and determined that, out of a combined population of 3,443 multiply handicapped children, over a third were totally blind. He found that the average child had 3.28 handicaps. The most common conditions were visual impairment, mental retardation, speech disability, and emotional disturbance.

With regard to the latter disability, a survey of behavioral problems in deaf school-age children at a state residential school for the deaf (Meadow and Schlesinger, 1971) revealed that 12% of the residents were considered by teachers and counselors to be seriously emotionally disturbed, and 3% were thought to be mildly disturbed. These results were confirmed by an informal census of day programs for the deaf which indicated that the proportions of severely and mildly disturbed students were about the same. From these data it would seem that the need for mental health services for the deaf far exceeds those which are available.

In the most recent study of deaf mentally retarded children reviewed for this paper, Steward (1972) cites prevalence figures which indicate that 20% to 35% of the 500,000 persons classified as deaf or hearing-impaired may be multiply handicapped. Thus, over this limited time period, there has been little change in prevalence estimates, which continue to range from 13% to 49%. Clearly the incidence of sensory deficits and other handicaps in the retarded, and conversely that of mental deficits in the visually and aurally handicapped, are considerably higher than in the normal population.

However, before turning from this section on prevalence statistics, it should be noted that, in their review of recent literature on children with both handicapping conditions, Anderson and Stevens (1969b) make the point that prevalence data are inconsistent due to the lack of agreement as to terminology, problems in assigning priority to one of the two concurrent disabilities, and lack of appropriate facilities for the deaf mentally retarded.

### 3.3 Research and Demonstration

The literature on the deaf-blind reviewed for this report reveals an almost complete absence of rigorous experimental research on educational or treatment issues. Ashcroft and Harley (1966) have reported on work with the visually handicapped child conducted between 1963 and 1965, and Greene et al. (1969) assembled a list of both medical and educational resource materials which are expected to be of help to teachers working with multiply handicapped blind children. The items cover topics such as identification, medical aspects, and the development of instructional technology and curricula. There are a number of surveys which point up the scarcity of existing programs and the inadequacy of those which do exist (e.g. Anderson and Stevens, 1970; Rodden, 1970; Hall and Talkington, 1972), but the majority of the articles comprise a collection of reports of demonstration or experimental programs, utilizing a wide variety of approaches. This may reflect the idiosyncratic nature of the problems, a creative flexibility in treating them, or an implicit indication that no one really effective procedure has as yet been developed.

It is extremely difficult to categorize these writings, even under the two loose rubrics selected, i.e., Curriculum Guides and Instructional Technology and Research and Demonstration Programs. There is a great deal of overlap. Reports of curricula and instructional materials often include descriptions of programs in which they were applied, and program innovators often describe the curricular components of the demonstration program.

3.3.1 Curriculum Guides and Instructional Technology. A number of accounts of techniques used with the deaf-blind are available in the literature. Robbins (1960) provides a detailed manual on the basic systems, such as Tadoma, Braille, and finger spelling. This 80-page booklet is based on the approach developed at the Perkins School for the Blind, and distills the essence of the school's long experience as the pioneer institution for the blind in the United States. It is a curriculum guide prepared especially for teachers of the deaf-blind and covers the full range of educational processes, including self-care skills, motor development, guiding principles, adaptive and intellectual growth, and language development.

In his report of an international conference on modern approaches to the diagnosis and instruction of multiply handicapped children, Prick (1971) includes a number of papers which are relevant here. Five of these deal with planning and development of programs for the deaf-blind, while specific teaching techniques are the subject of several others.

A radical application of instructional technology in the teaching of the deaf-blind is advocated by Guldager (1972). Strange as it may seem, Guldager recommends the use of videotape for child instruction as well as teacher training. This is based on the fact that most of those categorized as legally deaf and blind do have some residual hearing and vision. Videotape is also an invaluable tool for in-service training of the personnel working with the deaf-blind.

With deaf-blind children of normal mental ability the major problem is that of reaching the child so as to open up channels of communication. Once these sensory barriers have been surmounted, a great deal of progress toward normalization can be made. It is quite a different story when sensory impairment is accompanied by impaired mental functioning. From the educational and rehabilitation point of view, mental retardation is by far the greater handicap. Addressing the needs and limitations of the mentally retarded deaf child, Guppy (1972) presents a structured curriculum for teaching language and communication skills as well as for the development of personal and social adequacy.

Experimental Classes for Multiply Handicapped Deaf Children (1970) describes a six-week residential summer program for educable retarded deaf children between the ages of 8 and 12 years. These children had previously been rejected both from schools for the deaf-blind and those for the retarded, and many had had no formal schooling at all. The object of the study was to develop a program for multiply handicapped deaf-blind children for year-round use in the Indiana School for the Deaf. An incidental finding was that manual communication (signing) was superior to aural communication or lip reading.

A similar workshop is reported in Professional Preparation of Teachers of the Multiply Handicapped (1971). Four weeks of a six-week summer institute

at the University of Pittsburgh were devoted to the development of individualized curricula, specifically relevant to the needs of each of 12 deaf-blind mentally retarded children. Motor and communication skills and adaptive behavior were the principal content areas.

3.3.2 Research and Demonstration Programs. A trend toward early intervention with deaf-blind children seems to have gathered momentum with the 1964-65 rubella epidemic. There have been concerted efforts to locate the children of mothers who had had German measles during pregnancy and to identify those children who had suffered prenatal damage. Along with this organized search has gone an attempt to carry out more precise diagnoses and evaluations.

In developing programs for the rubella victims, three areas must be considered. The first is that of medical treatment, since most of these children suffer from other handicaps in addition to deafness and/or blindness. Second is the educational program. There is substantial research evidence that supports the need to establish communication channels as soon as possible, even in earliest infancy (e.g. Meadow, 1968). Finally there is the development of a long-term educational, vocational, or residential plan, depending on the progress made during the first educational experiences. Thus a multi-disciplinary approach which coordinates medical, psychoeducational, and long-term management is essential. (Cf. Stein and Green, 1972).

Several trends can be identified in the recent literature on the multiply handicapped-sensorially impaired. Related to the emphasis on early intervention already cited is the effort to involve parents in educational and therapeutic programs with their children, and to develop increased responsibility for the support of specialized programs. There is also a tendency to adopt educational rather than medical models for this population (Power and Quigley, 1971; Moor, 1968). In terms of treatment approaches, behavior modification and psychotherapy have been used with emotionally disturbed and mentally retarded deaf/blind children, and "total communication" in work with the deaf-blind. The latter technique seems to be favored by schools for the deaf-blind on the West Coast. This procedure utilizes every possible sensory modality to reach the handicapped child.

Since most deaf-blind children are unlikely to be totally lacking in both vision and hearing, efforts are made to use auditory training, speech, lip reading, finger spelling, and signing. As part of the "total communication" effort, particular importance is placed on teaching parents these techniques and involving them in the educational program. These and other educational methodologies indicate an increasing emphasis on individualized programming. A brief sampling of items representing these trends, several of which combine more than one emphasis, will illuminate the wide range in this literature.

The Rubella Project operated at New York University's Medical Center (MR 72: Islands of Excellence) is a totally eclectic, exemplary program employing the best diagnostic practices currently known. It is concerned with multi-sensory deprivation, and its clientele, defined as preschool children who have at least two major handicapping conditions, includes a number who are deaf-blind.

In a study of multiply handicapped deaf, Stewart (1971) provides additional support for an increased emphasis on preschool education, parent instruction in special communication techniques, stronger guidance and counseling programs for both parents and patients, more meaningful recreational programs in dormitories of residential schools, and greater involvement of teachers in a total educational program. (Also see Hairston, 1971).

Andrew and Feuerfile (1965) studied a rehabilitation program for the deaf-retarded. Eight patients served as controls while 24 with similar handicaps received 18 to 24 months of special training in communication skills, shop experience, physical education, and homemaking. Twelve of the 24 also received psychotherapy. Compared to the controls, the experimental group showed significantly greater improvement in social/personal adjustment but not in academic achievement. The psychotherapy program had no positive effect; in fact, the subjects without psychotherapy improved more in intellectual functioning and performance than those who received it. Some of the patients were able to be discharged or placed in the community on a day basis and others were able to participate in the institutional work program following treatment.

A study of a coordinated, pre-vocational, recreational, and residential living intervention program was conducted by Hall and Talkington (1973) with 18 aurally handicapped male residents of a public facility for the mentally retarded. The subjects were moved to a residential cottage where there were visual aids, amplification, and staff trained in manual communication and behavior modification techniques. An increase in sign vocabulary and significant improvement in grooming, communication, academics, recreation, responsibility, and social skills were observed.

Low staff-pupil ratio, application of behavior modification, engineered instruction using individualized, self-administered materials, coordinated classroom and dormitory activities, manual communication, and parent education were major features in a program for emotionally disturbed deaf boys at a residential school (Brill et al., 1969). It was designed to modify behavior and teach basic skills and subject content. Results show significant gains in class conduct and self control, and in reading and arithmetic. A two-year behavior modification program at the same residential school for the deaf was carried out by Lennan (1970). Seven of the 18 emotionally disturbed deaf boys in the Multi-Handicapped Unit progressed sufficiently to be transferred to regular classrooms in the residential school. The behavior modification techniques included positive reinforcement with gradual reward deferment (fading), check cards for all activities even during bus trips and home visits, and a staff-child ratio of one adult to four children. Both of these demonstration-research programs were judged successful and behavior modification is now a regular feature at this school.

Language and speech instruction as well as the acquisition of socially acceptable behavior was used with institutionalized blind retarded children by McClennen (1969) at the Plymouth State Home and Training Hospital in Michigan. An application of the token system of motivation was the goal of this program.

As reported by Wiehn (1970), the Michigan School for the Blind has for several years operated a very successful preschool program. A regular aspect of the program is a summer institute in which both children and their parents participate. After watching demonstrations by professionals, parents are given the opportunity to work with their own children so as to develop

skills in behavior modification and educational techniques in their own homes. More recently, an intensive workshop at the Michigan School focused on behavior modification techniques used with preschool deaf-blind children (Environmental Programming for the Deaf-Blind, 1972). Calvert et al. (1972) also report on the use of behavior modification techniques in the description of a four-year pilot program begun in 1966 at the San Francisco Hearing and Speech Center for preschool deaf-blind children. According to Calvert, who summarized the accomplishments of the program after four years of operation, operant conditioning had only limited value, and that was with children who had relatively unimpaired central nervous system organization. One of the major findings was that emphasis should be placed on total child development; another was that parents should be given support and counseling, not just training in communication skills.

Grinker et al. (1969) report the results of a research and demonstration project which applied therapeutic procedures to out-patients of a state institution for deaf mentally ill children and adults. In 58% of the cases the onset of emotional problems was found to be related to physical injury leading to deviant behavior, lack of motivation, severe ego defects, or separation or loss (or fear of loss) of persons or institutions with whom a dependency relationship had been established.

After two to four years in a special therapeutic program designed to match experiences to developmental levels (Ross, Braen, and Chaput, 1969), severely disturbed blind children demonstrated improved language facility, reduced anxiety, and increased mobility. Those who had been withdrawn and passive became more social and outgoing, whereas disruptive, acting-out children learned to redirect their energies and accept rules and limits. Most of the children progressed to the point where they could enter an appropriate academic program.

In order to understand the range of problems facing the multiply handicapped deaf child, a diagnostic teaching program was designed to relate physiological problems to educational needs, and thereby reduce the poor placement of multiply handicapped deaf children (Osborne et al., 1971). The unique characteristics of the program include 11 teachers and three teacher aides to 11 children, immediate attention to each child's amplification

needs, a daily one-half hour seminar for teachers, audiologists, psychologists, and a diagnostic teaching consultant.

O'Meara (1966) describes an experimental program for the developmentally delayed, visually impaired child at the Illinois Braille and Sight Saving School. A pupil-teacher ratio of 2:1 made possible individually prescribed instruction in living skills, sensory stimulation, and academic work, within the context of the residential cottage.

Findings by Rigby and Woodcock (1969) suggest that a group of five multiply handicapped blind children would be the ideal class size if the children were grouped according to functional ability. The recommendation is based on a study of a 12-month residential school, in which a Montessori curriculum provided opportunities for individual participation. Parent visits were seen to be beneficial in improving the child's self-care and social skills.

The need for early diagnosis and treatment of multiply handicapped deaf students was highlighted by Easson (1971) who studied symptomatic autism. The disorder is likely to occur when a child has been forced from infancy, or an early age, to live and grow in his private world due to a severe perceptual or intellectual handicap. The syndrome is most readily recognized in children who from birth or infancy are deaf, blind, or moderately to severely mentally retarded. Without treatment the child is likely to become increasingly handicapped and demonstrate bizarre behavior; eventually such a child is indistinguishable from children whose autism is due to other causes.

A nine-year-old congenitally blind girl had been placed by her own parents in special classes for the severely retarded, where her abilities were underestimated and she received little educational stimulation. She was removed from this depriving environment, placed in a foster home, and enrolled in the Simon Fraser Education Center. Her rapid progress in the acquisition of speech and language comprehension under these circumstances is cited by Rogow (1969) to emphasize the need for providing appropriate educational programs.

Generalizing from a study with 33 institutionalized blind-mentally retarded children, McDade (1969) believes that between 20% and 40% of persons with such handicaps can profit from a systematic orientation and mobility program. He suggests that while most aspects of training are similar for all blind children, both retarded and nonretarded, training the blind retarded child requires differences in time and level of presentation. It was also concluded that orientation and mobility training should be part of the curriculum in every institution housing blind, mentally handicapped persons.

The need to provide multiply handicapped children with stimulating and participatory learning experiences has been emphasized in a variety of environments. Thomas (1972) illustrated how multiply handicapped blind children learned to function independently in a variety of travel situations by providing instruction in coordination and postural exercises, sensory awareness, indoor orientation, travel skill building, and outdoor mobility in school and home neighborhoods, business areas, and on public transportation.

Terry and Schaffner (1972) report the success of a program of individualized curriculum, extensive motor development activities, development of interpersonal competence, and a home management program for visually handicapped retarded children aged three to eight years. The major objective of the program was to help children accept themselves, care for themselves, and handle problems independently. Similarly, Talkington (1971) reports an exploratory program which increased sensory behavior and motivation for 12 blind retarded adolescents residing in a public institution for the retarded. The program stressed sensory stimulation, communication, socialization, and mobility.

No studies contrast residential with home care in any controlled fashion. However, Smith (1972) states that the private facility is often better able to meet the special instructional needs of the multiply handicapped blind child, while public school special classes for the multiply handicapped blind child offer the advantage of living at home in a family setting.

### 3.4 Measurement

The use of mental ability tests with all children has received more and more criticism over the past decade. This has been particularly true with the deaf-blind whose sensory channels for receiving the test stimuli are so drastically impaired. In the past, researchers and psychometricians have designed various modifications to the traditional tests, such as the Binet and the Wechsler, and often performance measures such as the Leiter International Scale have been used. Two bibliographies of tests for the blind are described in the bibliography section, but these would not be relevant for those who are also deaf.

One of the most serious problems noted by Mitra (1970) in a survey of state residential facilities for the retarded is the absence of adequate diagnostic procedures. Most commonly, deaf retarded children are identified by consensus of the facility staff. When objective measures are used they usually include only traditional IQ and audiological tests.

Where there are handicaps in addition to impairment of vision and hearing, the task of evaluating competencies is even more complex. In cases of severe mental retardation, even the estimate of level of sensory deficit is difficult, and special techniques must be developed. Bricker et al. (1968) developed a manual to facilitate the use of operant audiometry with "difficult to test" children: i.e., those who are low functioning psychotic, severely retarded, or multiply handicapped. The manual contains instructions for determining reinforcers, physical facilities and equipment needs, technical descriptions, as well as instructions for the trainer-tester. (Also see Gruber and Moor, 1963; Moore et al., 1972; and Rosenstein et al., 1967.)

It may seem paradoxical that while evaluation in the affective domain with normal children has long been the bane of test constructors and psychometricians, social-emotional behaviors in emotionally disturbed deaf children can be more readily assessed. However, this is undoubtedly due to the visibility of extreme aberrance. Two institutional techniques which have demon-

strated their usefulness are the Rutter Child Behavior Scales and the Bristol Social Adjustment Guide (BSAG) developed by Stott. (See Green [1972] for a detailed description of these measures.) The BSAG provides a method by which teachers or observers can describe, in non-technical language, the type of information needed by psychologists or psychiatrists. Stott's Guide was the first commercially available instrument to be used with deaf emotionally disturbed children, and has proven successful in a number of research studies.

Criterion tests have been constructed to assess the level of achievement of performance objectives of specific programs. This is particularly true when, as at the Michigan School for the Blind, behavior modification procedures have been adopted. The Calvert et al. 1972 report on the San Francisco Hearing and Speech Center also includes a discussion of evaluation and diagnostic techniques such as audiometric testing and a behavioral profile (cf. Nicholas, 1972). To assess the affectiveness of remedial curricula it is often necessary to design measures which permit the diagnosis of existing areas of deficit in terms of entry behaviors, and then to chart the success of the instruction as increments in proficiency over time.

The CREED test battery (Restaino and Socher, 1969) was designed for such a purpose. It is used to measure gross motor coordination, sensory motor behavior, visual analysis, attention and memory, and conceptualization, with three to eight-year-old deaf multiply handicapped children. After testing over 1,000 children in schools for the deaf in New York State, significant differences were found in the performance of three age groups on all five subtests.

As these examples indicate, the task is simplified in programs using behavior modification and performance objectives. If a specific goal is set, and the specific components of that behavioral goal are described in small steps and prescribed on an individual basis, the evaluation of progress toward the goal is clear and straightforward. This seems to be the most promising solution for the assessment of children with multiple handicaps.

### 3.5 Guides to Providers

In a recent review of progress in the education of the deaf-blind, Guldager (1971) points out that only a few programs for deaf-blind children were in operation in the United States even as late as the middle of the 1960's and it was not until 1968 that a large-scale federal intervention program was initiated. This resulted in the establishment of the Regional Centers for the deaf-blind. The impetus for this federal support was directly related to the increase in exceptional children, including the deaf-blind, attributed to the 1964-1965 rubella epidemic.

The Deaf-Blind Regional Centers represent not only the first example of legislated federal support for the deaf-blind, but also the first autonomous facilities for this population. There are, of course, provisions for these children within larger institutions serving children with other handicaps, but the Regional Centers provide highly specialized techniques and a well coordinated system of services for habilitating deaf-blind children. In addition to developing programs and providing services, the Centers have conducted incidence studies and sponsored both regional and national workshops and seminars on various aspects of problems associated with treating the deaf-blind.

A brief discussion of the federal program, its criteria for eligibility, regulations, grant procedures, etc., are included in Policies and Procedures, published by the Office of Education, Bureau of Education for the Handicapped in 1969. Dantona (1970) summarizes the achievements of these Centers during their first year of operation, and Dantona and Salmon (1972) provide a more up-to-date overview of the Centers in a volume which includes appended listings of regional and national projects for deaf-blind children, youth, and adults. Guldager (1971) lists the coordinating agency and names the states for which each region is responsible.

Several regions have published lists of providers in their own areas, and these may be obtained by request from the appropriate regional office. (See Guldager, 1971, or Dantona and Salmon, 1972, for address.) Hammer (1970) has written a review of services in the region which includes Arkansas, Louisiana, Oklahoma, and Texas. Similarly the Southwestern Region Deaf-

Blind Center prepared a Directory of Programs (1971) which lists and describes public and private facilities enrolling deaf-blind children in Arizona, California, Hawaii, and Nevada. The information reported was obtained through a survey of school districts and private agencies.

Hayes and Griffing (1967) prepared a guide to public schools and institutions serving multiply handicapped deaf children in California; another Directory of Services for the Multiply Handicapped Deaf (1970), as well as bibliographies on projects relating to the multiply handicapped, is available from Gallaudet College. Schools and Classes for Deaf Children Under Six is a geographical listing of 343 teaching facilities compiled from 1967 survey data (Volta Review, 1967). Finally, Behrman and Moll (1965), in their Directory of Catholic Special Facilities, indicate which providers will accept deaf-blind persons with multiple handicaps.

### 3.6 Bibliographies

There have been a number of bibliographies on work with the blind and, separately, work with the deaf. Morris and Nislan (1971) prepared a bibliography of tests and testing of the blind, including over 400 items which appeared between 1920 and 1971. They cover the history, theory, and administration of tests either adapted or specially constructed for this population. A separate bibliography (Nolan et al., 1971) provides a complete picture of the history of research on Braille since 1907. The Council for Exceptional Children, in its Exceptional Child Bibliography Series, has issued two bibliographies on the "Aurally Handicapped," one covering Programs and the other Research (1972).

These do not exhaust the bibliographical resources in either of the two disability areas, but they have been included here since bibliographies on the deaf-blind are very difficult to find. Farrell (1956), in his general review of the field, includes a list of references which date back to the 16th and 17th centuries, but this can hardly be considered a bibliography.

McIntyre (1968) lists 400 items on the deaf and hard of hearing published between 1950 and 1968. They include reports, manuals, journal articles, curriculum guides, and instructional and audiovisual materials. The entries are arranged by subject area and include a section on the

multiply handicapped deaf and one on the deaf-blind. The only bibliography specifically addressed to the deaf-blind is the one prepared by Hammer (1969). For the multiply handicapped blind, the Rocky Mountain Special Education Instructional Materials Center has prepared a list of references designed to be of practical help to professionals working with this population (Greene et al., 1969).

The scarcity of bibliographies on the deaf-blind and the multiply handicapped deaf-blind indicates either a lack of work in this area or pinpoints a specific research need.

#### 4.0 SEVERE MULTIPLE HANDICAPS

##### 4.1 Problems of Definition and Classification

It is often noted, in the discussion of one type of disability, that there is a high probability that other types of handicaps will also be involved. Whether several problems result from the same cause or event, or whether one handicap produces another in a chain reaction, certain types of disabilities frequently are observed in the same persons.

Furthermore, the question of establishing cut-off criteria for determining what constitutes severity in a specific disability is difficult enough when there is only one handicap. How much more difficult it is when several handicaps are involved!

In addition to those multiple handicaps which consist of a combination of two or more handicaps, involving deaf-blind, emotionally disturbed, and mentally retarded, there is a fourth category, known generally as the "multi-handicapped," which comprises a combination of sensory, mental, and physical problems. These may include brain-damaged, cerebral palsied, and/or orthopedically handicapped children, as well as one or more of the three handicaps listed above. The problem of establishing severity in this category is, of course, multiply compounded.

A bibliography prepared by Lazar et al. (1967) lists 118 research studies, instructional guides, and curricula for the multiply handicapped. Lance (1967) reports the proceedings of a special DHEW study institute for this population. While the institute was primarily directed to reviewing

the work done in the state of California, the papers include a discussion of trends concerning services to the multi-handicapped generally and the multiply handicapped deaf in particular. A variety of topics of general interest deal with legislation, teacher preparation, parent problems, and curriculum development for both public schools and special classes.

Probably the most comprehensive treatment of the multiply handicapped child is included in the collection of papers edited by Wolf and Anderson (1969). An overview treats the medical and educational problems which must be met in these children, especially with the increasing number of congenital malformations resulting from the rubella epidemic, and also from the much larger number of premature or congenitally damaged children who formerly would have been aborted or lost soon after birth, but who are now kept alive by advances in medical science. The multiple disabilities discussed include combinations of deafness, retardation, cerebral palsy, blindness, and learning disorders. The incidence figures from a survey in Georgia are cited, indicating 2.2 handicapping conditions per child identified as multiply handicapped. Of particular interest is a suggested taxonomy, based on areas of functioning. The major categories are: somatic, intellectual, behavioral, and communicative. A rating system is devised in which one point for each of these categories or a total of four points can be counted for the following nine areas: physique, upper limbs, locomotion, hearing, eyes, speech, toilet, intelligence, and behavior. This procedure provides a numerical basis for estimating severity, with a score of 36 indicating the highest degree of impairment. Graham (1967) has also devised a severity rating scale based on the assignment of numerical values to various handicapping characteristics.

#### 4.2 Research and Demonstration

4.2.1 Curricula and Instructional Guides. Matteson (1972) sets forth practical guidelines for the use of motor development activities in conjunction with music in teaching multiply handicapped children. A more comprehensive approach is presented in An Early Childhood Curriculum for Multiply Handicapped Children (Schattner, 1971). The guide is addressed to

teachers and aimed specifically at preparing children aged four to nine years for academic learning in a school setting. Discussions of early identification of multiply handicapped children, the ideal physical plant, the special education classroom, and the role of parent-teacher cooperation are also included. A similar guide was prepared by Ball (1971) and contains suggestions for methodologies, media, and sample curricula for severely multiply handicapped children and profoundly retarded children. Instructional plans are presented for each of the following areas: ambulation, stimulation, communication, self-help skills, imitation, and behavior problems. Each plan includes a description of objectives, prerequisites, instructional methods, learning activities, and comments relating to perceived strengths and weaknesses. The guide concludes with a discussion of theoretical considerations involved in curriculum planning.

4.2.2 Demonstration Programs In addition to guides describing treatment techniques, several descriptions of programs for multiply handicapped children were reviewed. One of these, a rural home-based intervention program serving 75 multiply handicapped children between the ages of zero and six years, was described by Shearer and Shearer (1972). Each parent and child are visited once a week at home by a teacher who prescribes and demonstrates an individualized curriculum, which is implemented by the parents. The parents are also required to keep a daily log of the child's behavior. Shearer and Shearer maintain that in addition to providing strong empirical evidence that handicapped children can progress beyond what is usually expected of them, program results also show that parents can initiate, observe, and accurately record behavioral changes in their children.

A very different model is presented in An Educational Program for Multihandicapped Children (1972). This is a program operated by a school district for children aged three to eight years. In addition to describing the total educational programming, personnel requirements, and operational contexts inherent in this model, the paper presents the basic philosophy, including operational and educational goals, profile scales, use of media and curriculum materials and facilities.

Newcomb (1971) describes a program of services for very young multiply-handicapped children and infants at the Seal Bluff Development Center. Most of the children have mental retardation as one of their handicapping conditions, and the underlying philosophy is that early prevention and instructional programming can preclude the development of the secondary characteristics associated with retardation and brain damage. Like the rural program described by Shearer and Shearer (1972), the Center's approach relies heavily on home visitation. Volunteers make these visits, set up developmental milestones for the children, and train parents to implement the instruction to achieve the milestones. The basic curriculum, which is tailored for each child, includes development of motor abilities, stimulation of senses, teaching of body parts and self-concept, recognition of size and shape of concrete objects, and auditory and visual discrimination and perception.

Individual programs for day and residential cerebral palsied children (Frampton et al., 1969) were successful in helping children who had been considered untrainable to develop self-care skills. Using physical therapy, personality and language development, and parent involvement programs, the experimental school recommends a total clinic, multi-focal, school approach. Other suggestions are offered by Ashcroft (1966), who describes an experimental half-day program for the multiply handicapped child. Specific procedures which have been used in developing social competence are described.

In general, there are few rigorous experimental studies with the multiply handicapped. Research and demonstration programs tend to stress coordination of parental and professional efforts, and home care is favored over institutional placement. As with the deaf-blind, there is only a limited use of behavior modification procedures.

## 5.0 RESEARCH ON ALL SEVERE HANDICAPS

### 5.1 Problems of Definition and Classification

Because of the extreme importance of these problems, they are discussed as they apply to the individual handicaps in each section (1.0-4.0) of Part II. They are also treated extensively in Part I of this report. Thus, this important problem is only briefly discussed here.

Several investigators have concerned themselves with establishing guidelines for categories and levels of severity for the exceptional child, including all types of handicapping conditions. Engel (1969), supported by the work of Iscoe and Payne (1972), takes the position that there is an historical basis for the current dilemma. Research in each area of handicap has proceeded under the aegis of a different combination of disciplines, and it is the semantic confusion engendered by the various jargons of genetics, medicine, psychology, psychiatry, pathology, biochemistry, and other interested specializations, which is the major impediment to clarity of definition and classification.

Exceptional Pupils (1968), published by the Indiana State Division of Special Education, includes a chapter on issues of classification and measurement, and a workshop on the education of the exceptional child (Hall and Sieswerda, 1972) emphasizes the need for criteria for identifying the characteristics of various handicapping conditions. Van Osdol (1971) and Boston and Hanna (1971) have published glossaries of terms used by specialists working with exceptional children; they also include definitions and descriptions which relate to various classification systems.

## 5.2 Prevalence Studies

Because of the public pressure for the development of appropriate legislation to protect the rights of exceptional children and youth, and because sufficient funds must be allocated to ensure adequate service, a number of surveys have been carried out to estimate the size and characteristics of the population for whom special services will be needed. Some of these surveys have been under the aegis of the federal government while others have been commissioned by states, local communities, or special organizations.

Trapp and Himelstein (1972) summarize the data from a survey conducted in 1968 by the U.S. Office of Education, Bureau of Education for the Handicapped. These data indicate that 80% of the approximately 5,224,705 handicapped children between 5 and 17 years of age suffer impairments of speech, mental retardation, or emotional disturbance. A further analysis indicates that 1,767,380 of these handicapped children were in local public schools,

133,932 in residential or state schools, and 3,323,393, or more than 63%, were not being served. It should be pointed out that these data are not census figures but estimates based on inferences from population statistics. Furthermore, the first figure refers to 1968 data, and the second is derived from applying the same probability ratios to 1966 data.

In 1973, the Bureau of Education for the Handicapped estimated that there were approximately 7,000,000 handicapped children, of whom only 40% were participating in some sort of special program. While the bases of these two estimates may not be comparable, there is certainly some reason to believe that, although the number of identified handicapped children and youth is increasing, this rate is less than the rate at which facilities for providing needed service are being developed. Presumably at some point in the future the demand will be met, but there is still a long way to go before all handicapped persons enjoy the rights guaranteed them under the Constitution.

There are continuing efforts to achieve this goal. Several national studies are now under way to obtain a clearer definition of the population needing services and to assess those services which are available. One of these is the Evaluation of Educational Programs in State-Operated and State-Supported Schools for Handicapped Children (P.L. 89-313) now being completed by Exotech Systems, under contract to BEH. This report will include the most recent estimates of the target population of handicapped children as well as the P.L. 89-313 grant formula and grant program data (Phase I Report, 1973).

Another is a comprehensive compilation of services for handicapped youth (Kakalik, 1973). This is a 20-month cross-agency evaluation of federal and state programs for both mentally and physically handicapped youth in the United States. It will provide estimates of prevalence together with a description of the resources presently available to meet the needs of this population. It will also attempt to develop some definitional guidelines for classification of handicaps.

Other federal contracts for surveys of various segments of this handicapped population were let in July, 1973. A clearer picture of prevalence,

need, and services available should provide a sound basis for future action.

### 5.3 Measurement

It has been noted in many contexts that a major obstacle to experimental research, classification, treatment, cost analyses, and prevalence estimates is the absence of valid measures to use with handicapped children.

Even with normal populations, where the standardized intelligence tests have some modicum of acceptance, there is a great deal of criticism when they are used to assess the mental abilities of minority children or those from different cultural and ethnic backgrounds. Although the intelligence test is the major single criterion for classification in mental retardation, the need to include measures of social and emotional adjustment has been repeatedly stressed.

In an article which explores the relationship between classification and measurement (Pedrini and Pedrini, 1972), the point is made that tests should help, not harm, the person tested. Often test results are used to stigmatize handicapped children as incapable of learning, thus releasing teachers from their responsibilities. This constitutes a perversion of the diagnostic-prescriptive purpose of testing, which is to identify areas of competence which can be enlisted in the remediation of identified areas of deficit.

There is clearly a need for the development of diagnostic assessment techniques which can be used in planning appropriate programs for exceptional children, and a great many researchers have addressed themselves to this problem. Where the measures reported were created for a specific handicap they have been discussed in the appropriate section. In addition, a number of investigators have compiled collections of tests for handicapped children in general.

Swassing (1969) has published a list of instruments which were used in end-of-year evaluations of projects funded under Title VIa and P.L. 89-313. These reports were submitted by 50 states and six territories at the end

of the 1968 school year. None of the tests listed were considered adequate, and Swassing recommended that new measures should be developed for future evaluation of the handicapped. An anthology of fugitive and standardized tests (Cook, 1971) is available from the Department of Public Instruction Library in Madison, Wisconsin. The anthology, which consists of over 300 items, was designed for special education administrators, teachers, and program planners. In addition to standardized, commercially available tests, it includes evaluation measures especially designed by researchers to meet the needs of various studies with handicapped populations.

Tarczan (1972) has compiled a set of psychometric procedures which can be used with handicapped persons. The text includes a discussion of psychodiagnosis, the intelligence quotient and concepts of mental age, a glossary of psychometric terminology and testing terms, as well as a directory of standardized tests. Unfortunately, none of the measures listed are appropriate for severely handicapped persons.

Kafafian suggests that this technology can also be adapted for use in evaluation. Since most of our traditional approaches to measurement have proven inadequate, this new direction certainly merits further exploration.

#### 5.4 Guides to Providers

There are several directories which contain listings of services available to a number of categories of handicapped children. None of these is devoted to services offered specifically to severely handicapped individuals, although there is some attempt to indicate three levels of severity for certain disabilities such as mental retardation and emotional disturbance.

Several of the directories reviewed are nationwide in scope. Probably the most comprehensive of these, the Directory of Facilities Providing Special Education in the United States (1973), is based on a survey conducted by the National Special Education Information Center during 1970. It contains descriptors for over 3,000 programs, excluding those under the jurisdiction of State Departments of Education. The facilities are listed alphabetically by state, within each of several handicapping conditions. These include autism, deaf-blindness, emotional disturbance, mental retardation, and multiple handicaps, as well as other types of handicaps not

relevant to this review. For each program or facility, the following information is given: name, location, control, licensure, ages accepted, separation age, day or residential service, primary and associated handicaps served, handicaps excluded, programs provided, and test services. All the relevant data have been coded into a computer system. It can be accessed and printouts requested for a number of dimensions or combinations of dimensions. For example: "state and private residential programs serving deaf-blind preschool children in California." An updating of this excellent resource system is now in progress.

Another comprehensive national index is the Directory for Exceptional Children, issued by the Porter Sargent Company. It is revised periodically and a seventh edition was published in 1972. Nearly 4,000 facilities for the handicapped are listed, with the following information for each entry: name, address, name of director, enrollment data, handicaps served, staff, educational programs, rates, ownership, and sponsorship. It also contains area maps, announcements from about 70 institutions, a list of associations, societies, and foundations, and federal, state, and territorial agencies serving the handicapped.

A listing of the number and kinds of children's residential institutions in the United States (Star and Kuby, 1967) was prepared for the Project on Physical Facilities for Group Care of Children. The types and auspices of voluntary and proprietary, public and private institutions were culled from a master list published by the Center for Urban Studies.

Catholic-affiliated facilities and programs are referenced in a directory prepared by Behrmann and Moll (1965). The directory lists clinics, centers, and hospitals offering specialized services to children with emotional-social disturbances, mental retardation, and multiple handicaps. State training schools, hospitals, and institutions are also indexed.

Diagnostic facilities and programs offering remedial, therapeutic, and developmental services for learning disabled and other handicapped persons are listed in the Directory of Facilities for the Learning Disabled and Handicapped (Ellingson, 1972). Because of the nature of its focus, probably few of the providers would accept the most severely handicapped.

In addition to directories which are nationwide in scope, individual states issue directories of services for handicapped persons offered through various state departments, such as Education, Mental Health, or Social Welfare. Addresses of the appropriate offices are listed in the Porter Sargent guide. They may also be obtained from the Council for Exceptional Children in Arlington, Virginia.

The Council has published guides to selected government (federally funded) and public agencies (Glassman and Erickson, 1972). The latter includes 90 organizations involved with exceptional children and provides information on membership requirements, sponsorship, and local chapters.

An early guide to Services for Handicapped Children (1955) presents a comprehensive listing of the various types of special services, facilities, and centers available. Although this is now probably out of date, it is interesting in that it also contains a discussion of problems common to various handicapping conditions and emphasizes the need for organizing communities to provide an integrated program of services.

## 5.5 Cost of Services

5.5.1 Cost Surveys and Studies. Extensive data on costs of programs for the handicapped have been collected by the National Institutes of Mental Health, DHEW Division on Developmental Disabilities, the American Association on Mental Deficiencies, and by state, private, and citizen groups.

Among these various reports there are dramatic differences in the estimates of number and types of handicapped persons, the number and quality of institutions, and in the amount spent to maintain an institutionalized person. The average daily per resident costs in 1970 ranged from a low of \$4.61 to a high of \$16.38. There are also considerable variations in the way the funds are allocated and in expenditures for new construction or facility renovation (e.g., see Mayeda, 1971). These figures, however, are virtually worthless for comparison purposes since the accounting and accrual bases on which they are computed are far from consistent. They do, nevertheless, provide some indication of the range of costs associated with the care and treatment of handicapped children and youth.

Just as mental retardation has received the greatest amount of research attention, so too has the question of costs of care in facilities for this population. There are several excellent references devoted entirely to this issue for this handicap category. The summary presented here relies heavily on the work of Kugel and Wolfensberger (1969), the Mental Retardation Source Book (1972), and Conley (1973).

The cost of residential care is completely disproportionate to that of non-residential care. Although only 5% of the retarded population is institutionalized, more funds are allocated to maintain them than are spent for the public programs which serve the remaining 95%. And these costs are rising precipitously. Costs of operating and maintaining public residential institutions increased almost 300% since 1960, exceeding \$870 million dollars in 1970. The average cost per patient was approximately \$4 in 1960, \$6 in 1969, and \$12 in 1970.

The cost of non-residential care has also risen alarmingly. The per pupil cost in special education classes increased more than 25% between 1968 and 1970, so that the cost per child was over \$1600 per year, compared with that of approximately \$450 per year in a regular class. Unfortunately, these increases are due primarily to inflation and do not represent any increase in the quality or comprehensiveness of the services provided.

Costs of services vary with the age and level of severity of the population being served. Operating costs per student in non-residential classes for the severely retarded are approximately three times the cost per student in classes for the educable retarded and almost six times the cost of students in regular classes. The higher costs for the severely retarded reflect high staff-to-pupil ratios, excess transportation, and special therapeutic services. Even in residential settings, costs vary with age and level of severity of handicap. Thus the number of residents per staff member decreases as the percentage of severely and profoundly retarded increases; correspondingly, costs increase with an increase in the number of residents under 20 years of age. Results of a log linear regression analysis indicate a cost difference of \$2,100 per year between adult and child residents, and a cost difference of \$400 to \$900 per year between the profoundly and severely retarded and those with mild or moderate retardation.

There are also considerable differences in the cost of services in public and private facilities. During the period when the average reported per capita cost in public institutions was about \$6 per day, the cost of comprehensive care in a private or special residential center was estimated at over \$60 per day. This wide discrepancy may be due to the fact that these providers typically serve younger children and provide developmental care, which means special teachers, therapists, medical doctors, and other professional personnel.

Much of the cost data for the care of the mentally retarded also apply to the care of emotionally disturbed children. Conversely, the report of the costs in the Residential Treatment Centers (RTC's) prepared by Witkin and Cannon (1971) can also be generalized to offer insights into the costs of residential care for a variety of handicapped populations. A number of excellent reports with additional cost data are referenced in the RTC article, e.g. Taube's "Expenditures in Private Mental Hospitals and Residential Treatment Centers For Emotionally Disturbed Children" (1970), but the Witkin and Cannon study is the most complete and the most recent.

The data reported were collected by the Biometry Branch of the NIMH, with the cooperation and assistance of various state mental authorities. In addition to the 261 RTC's, the survey instrument, Inventory of Mental Health Facilities, was mailed to public and private mental hospitals, general hospitals with psychiatric wards, out-patient psychiatric clinics, mental health day care facilities, community mental health centers, and multi-service psychiatric facilities. Of the 686,000 emotionally disturbed children identified in the survey, 77% were receiving psychiatric care in an outpatient clinic, while 91,000 or a little over 13% were in some type of residential facility. Forty percent of the latter group were placed in general hospitals, 28% in state and county mental hospitals, 8% in community health centers, 8% in private mental hospitals, and 16% in the RTC's. Although some comparisons among these different types of providers are made, the study focuses on the analysis of costs and services in RTC's.

It should be noted that RTC's are far from being a homogeneous group; rather each has its own unique identity and may differ widely in terms of treatment approach, staffing functions and ratios, administrative organiza-

tion, etc. A certain amount of extrapolation and adjustment was necessary before any meaningful tabular data could be set up.

Expenditures are grouped under three headings: salaries, other operating expenses, and capital expenditures. It was estimated that the RTC's spent over \$121 million during 1969; of this, 56% went into employee salaries. In comparison, psychiatric hospitals for children and state and county mental hospitals allocated approximately 75% of their total budget to salaries, and the private mental hospitals 61%.

The average per capita cost per day in an RTC was \$27, whereas the average cost in a public mental hospital was \$14, in a private mental hospital \$49, and in a psychiatric hospital for children \$66 per day. The salary components of the per capita figure were \$15, \$20, \$30, and \$50, respectively. On the average, RTC's expended 12% of their budgets on capital investment; however, this figure is weighted by the fact that 32% of the RTC's reported no capital expenditures at all.

Among RTC's, average per child costs varied with the number of children and the geographical location of the facility. RTC's with less than a 25% bed capacity averaged \$36 per resident; from 25-74 beds, \$30; and with 75 to 99 beds, \$19 per person per day. It is interesting that when bed capacity rose over 100, the per person costs increased to \$23 per day. With respect to geographical location, the highest costs were recorded in New England (\$37) and the lowest in the West South Central area (\$11).

5.5.2 Variables Affecting Cost Estimates. While the reporting of census and cost information has improved considerably, as demonstrated in the Witkin and Cannon study, no real progress can be made in estimating costs of services as long as these continue to be tied to categorical descriptions of handicaps rather than the nature and extent of deficit and the nature and amount of service required.

Unfortunately, whether public or private, every type of facility must develop some method of computing costs so as to provide guidance in budget and program planning. Given the absence of reliable data on operating costs by function, administrators may attempt to compute costs

by dividing total expenditures by the number of persons served. For many reasons this procedure has serious drawbacks:

- It assumes that budgeted costs are actual costs, and does not take into consideration variations in the length of program years, scope of services, amount of service actually provided, or the time when service is available.
- It fails to take into consideration the cost of processing new admissions, which usually absorbs a large share of the operating funds.
- It includes the costs of capital investments such as furniture, equipment, vehicles, and renovations, which should be amortized over a longer time period.

Many fiscal reports do not distinguish between costs and expenditures. Valid cost comparisons require that all expenses be defined and accounted for. Thus, all goods and services provided in a program must be included as a cost, whether they are paid for in cash or contributed. A frequently overlooked cost component is the value of unpaid patient services. Many facilities require that residents spend time in maintaining the grounds and buildings, in food preparation, laundry, etc. Where the population is too young or too severely handicapped to participate in these types of activities, non-resident help must be employed. This contributes to the spuriously higher cost figures frequently found in facilities serving younger, more severely handicapped patients.

Another source of inaccuracy in estimating cost is the failure to include the true market rental value of land, buildings, and equipment. This element of cost is almost always omitted from operating expenditures of public institutions, since these assets are usually owned by the state or sponsoring agency, rather than rented. Also, many facilities are eligible for food subsidies and other types of special allowances which, by lowering the expenditures, misrepresent the actual cost.

In facilities which are part of a larger institution, such as psychiatric care provided in a general hospital, the computation of costs is confronted by the need to estimate costs proportionately to the share of space, time, and services received. What percentage of the salary of a receptionist, of the switchboard operator and the telephone charges, of

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maintaining the building grounds and common areas, should be charged to the mental health facility in a community health center? Such questions are extremely difficult to answer, and yet the cost of the items cannot be simply written off, otherwise the cost of providing services within a larger setting will appear comparatively low.

5.5.3 Cost Data Collection Procedures. Although precise information on the cost of services to severely handicapped children and youth are not yet available, techniques for collecting cost data for both residential and non-residential providers have been refined and extensively tested since the early 1960's. Elkin and Cornick (1969) report a detailed system for analyzing costs in a residential group care facility. Their work represents the product of a three-year project funded by the Child Welfare League and the Children's Bureau. The study was designed to develop and evaluate a computer based cost analysis system. A modified version of this system was applied in a study of 21 children's institutions in the metropolitan Chicago area, and in eight Pittsburgh institutions. More recently (1971-73) researchers at Abt Associates, Inc. have developed functional cost analysis procedures for non-residential child care programs and have gathered extensive data on the costs of various types of delivery systems. The latter studies have resulted in the development of categories of mutually exclusive functions that are truly representative of program activity clusters. Key analytic procedures are then used to attribute personnel time to specific program functions.

#### 5.6 Status of Current Legislation and Litigation

A digest of State and Federal Laws relating to the education of handicapped children was prepared by Trudeau (1972), and Weintraub et al. (1972) have prepared A Model Law for the Education of Seven Million Handicapped Children.

The major piece of legislation dealing specifically with the deaf-blind is Public Law 90-230. This law, which called for the creation of regional centers for deaf-blind children, is an amendment to Title VI, Part C of the Elementary and Secondary Education Act. In 1970 it became part of the Education of the Handicapped Act.

In general, however, writers have focused to a large extent on protecting and strengthening the civil rights of handicapped children and adults (Weintraub, 1971; Allen, 1971; International League of Societies for the Mentally Handicapped, 1969). A number of landmark court decisions have affirmed the public responsibility to provide education and treatment to all handicapped persons. The court decisions in many cases have substantiated the right of handicapped persons to equal protection under the law, including being provided with an education and full rights of notice and retention in educational programs. Abeson (1973), in the most recent of a continuing series of reviews sponsored by the Council for Exceptional Children, covers litigation concerned with the education of all handicapped children and youth. The next section summarizes some of the important litigation, both pending and completed, having significant implications for the education and treatment of all handicapped persons but with major emphasis on the mentally retarded. These cases deal with the issues of right to education, right to treatment, and right to protection from harm.

#### 5.6.1 Right to Education.

Pennsylvania Association for Retarded Children vs. Commonwealth of Pennsylvania. Civil Action #71-42 (3 Judge Court, E.D., Pennsylvania). This case represents the first important legal breakthrough in establishing the right of all retarded children to a free public education. The plaintiffs in this class action were the Pennsylvania Association for Retarded Children, 14 named retarded children who were denied an appropriate education at public expense in Pennsylvania, and all other children similarly situated. This group brought suit against Pennsylvania for the State's failure to provide all retarded children access to a free public education. The opinion and order in this case stated that no child could be denied admission to a public school program or have his educational status changed without first being accorded notice and the opportunity of a due process hearing. Furthermore, it was decreed that no state could apply laws which postpone, terminate, or deny such children access to a publicly supported education, including a public school program, tuition or tuition maintenance, and homebound instruction. This decision strengthened the position that all mentally retarded

persons are entitled to an education, regardless of the severity of their handicap. As stated in the consent agreement:

Expert testimony in this action indicates that all mentally retarded persons are capable of benefitting from a program of education and training; the greatest number of retarded persons, given such education and training, are capable of achieving self-sufficiency, and the remaining few, with such education and training, are capable of achieving some degree of self-care; that the earlier such education and training begin, the more thoroughly and the more efficiently the mentally retarded person will benefit from it; and, whether begun early or not, that a mentally retarded person can benefit at any point in his life and development from the program of education and training . . . It is the Commonwealth's obligation to place such mentally retarded children in a free, public program of education and training appropriate to the child's capacity within the context of a presumption that, among the alternative programs of education and training required by statute to be available, placement in a regular public school class is preferable to placement in any other type of program of education and training.

Mills v. Board of Education, Civil Action #1939-71 (District of Columbia), expands the principle of the landmark Pennsylvania "right-to-education" case by including the right to a public education for all children suffering from mental, behavioral, emotional, or physical handicaps or deficiencies, not only for mentally retarded children. While the Pennsylvania case rested upon a consent agreement between the parties, the Mills case is a pure constitutional holding, and thus has even stronger precedential value. The judgment specifies that the District of Columbia shall provide to each child of school age a free and suitable publicly supported education, regardless of the degree of the child's mental, physical, or emotional disability or impairment, and that insufficient resources may not be a basis for not fulfilling this obligation.

#### 5.6.2 Right to Treatment

Wyatt v. Aderholt, 334 Supp. #1341 (M.D. Alabama, 1971), 32FF. Supp. #781 (M.D. Alabama, 1971), and Burnham v. Department of Public Health, Department of Public Health Civil Action #16385 (U.S. District Court, N.D. Georgia). In both the Wyatt and Burnham cases, where appeals are presently being heard, it is argued that there are three basic constitutional provi-

sions which establish the right of an involuntarily confined patient to treatment:

- (a) Due Process: The 14th Amendment states that no person can be deprived of liberty without due process of law. The fundamental fairness doctrine under due process of law requires that treatment, and not mere custody, be the necessary quid pro quo for a patient's loss of liberty.
- (b) Equal Protection of the Laws: The 14th Amendment also prohibits denial to any citizen or group of citizens equal protection of the laws. Under this provision, classifications of citizens must be reasonable. Classifying persons as "mentally handicapped" and subsequently depriving them of their liberty is reasonable only if treatment is provided.
- (c) Cruel and Unusual Punishment: Since civil restraint of a mentally handicapped person without treatment amounts to punishing him for his sickness, such commitment violates the 8th Amendment which prohibits cruel and unusual punishment.

#### 5.6.3 Right to Protection from Harm

New York State Association for Retarded Children, et al. v. Rockefeller, 72 Civil Actions #356 (E.D., N.Y.); and Patricia Paresi, et al. v. Rockefeller, 72 Civil Actions #357 (E.D., N.Y.); both filed March 17, 1972. In a recent memorandum and order on the plaintiffs' motion, the judge declined to rule that mentally retarded residents of Willowbrook State School for the Retarded have a constitutional right to adequate habilitation. He did, however, find that they have a constitutional right to be free from harm, and ordered appropriate relief. Rights of persons in confinement were outlined by the court and include the right to protection from assaults by fellow inmates or staff, the right to conditions consistent with "basic standards of human decency," the right to medical care, the right to exercise and have outdoor recreation, the right to adequate heat during cold weather, and the right to the necessary elements of basic hygiene.

The fight for the recognition that every human being has an equal right to the fulfillment of his potential, regardless of the severity of handicap, is perhaps the most important development in the field of special education in the present century. It has resulted in increasing the available

monetary resources for research and experimentation as well as for the improvement of facilities for all types of handicapped persons. The litigation and the legislation continue; the fight is by no means won, but there is a new spirit of hope and a feeling of optimism that not only will the lot of the handicapped be immeasurably improved, but a reciprocal benefit will be provided to society.

### 5.7 Bibliographies

The Council for Exceptional Children, in its Exceptional Child Bibliography Series, has published over 50 Selected Bibliographies. A list of the titles can be obtained from the Council offices. These bibliographies consist of a computer printout of the items on a particular topic abstracted by the Information Center on Exceptional Children, which is one of the network of Educational Resources Information Centers funded by the Office of Education. Many of the selected bibliographies are concerned with the severely handicapped.

In addition to the Bibliographies, the Council publishes Exceptional Child Abstracts, a journal which focuses specifically on work concerned with the handicapped, as well as collections of papers presented at the yearly conference of the Council for Exceptional Children. These papers cover the entire gamut of topics in the field of special education, including research, exemplary programs, curriculum development, etc., all having to do with handicapped children and youth. While the entire range of impairment is included, a great many of the items are addressed specifically to the severely handicapped.

Other compilations of research have been edited by individual researchers. Thus Goldberg (1967) has a selected bibliography of special education which references items on a variety of handicaps. Hurder (1970) reviews research projects conducted in the United States during the 1960's. The primary focus is on the education of emotionally disturbed, mentally retarded, deaf-blind, and multiply handicapped children.

Textbooks on special education or the exceptional child invariably are excellent bibliographical resources. Trapp and Himmelstein (1972), Cruikshank and Johnson (1967), and Dunn (1963) are examples of this type of

reference. Additionally, annual reviews of research, the two editions of the Handbook of Research on Teaching, and the Mussen edition of Carmichael's Manual of Child Psychology illustrate some of the settings in which bibliographies, and bibliographies of bibliographies, are to be found.

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