

AN HISTORICAL AND DEVELOPMENTAL PERSPECTIVE OF COMMUNITY
CONTINGENCIES THAT AFFECT THE THRUST TOWARD
SELECTED SERVICES FOR THE MENTALLY RETARDED

A Dissertation

Presented to

The College of Education of the
University of Houston

In Partial Fulfillment
of the Requirements for the Degree
Doctor of Education

by

Frank A. Borreca

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A study of the major factors that effect the treatment of mentally retarded persons within their home community reveals how incredibly complex and many-faceted is this problem we so simply sweep under the term "mental retardation."

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ABSTRACT

The purpose of this study was to identify, from an historical and developmental perspective, the major factors which had a significant effect upon public policy and treatment services for the mentally retarded; the various social philosophies underlying the decision-making process in this problem area; and their relationship to the service-model trends now emerging.

A comprehensive review was made of the historical development of public residential institutions, the passage of significant Federal and State legislation pertaining to the retarded, and the development of self-organized volunteer parent groups. In order to ascertain the effect that these factors had upon the development of community services for the mentally retarded, the evolution of a local parent group and the subsequent development of a community agency for the retarded in Houston, Texas was examined.

There is evidence that while many beneficial changes have taken place, society's attitudes toward deviancy remains the single dominant factor in shaping present and future patterns of care for the retarded in the United States.

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CHAPTER I

BACKGROUND REVIEW OF PROBLEM

INTRODUCTION

Mental retardation, until recent years a concern mainly of professional persons confronted by the problem in their daily work, has emerged as a subject of unprecedented interest and involvement of our general society.

Recent efforts of political leaders, acts of Congress, and commitments of parents have resulted in significant action programs at the Federal, state, and community levels. While diverse in direction, these action programs have decidedly affected decision making in relevant social systems.

States are evaluating existing programs and developing plans for the future. Communities are beginning to recognize that the problem of retardation is more than a family responsibility. There is a realization that the syndrome of retardation transcends any single profession, that adequate and comprehensive programming will require the cooperation and collaboration of a host of disciplines. Non-professional interest groups, consisting mainly of families of consumers of services, are being included in major advisory and decision-making citizen bodies affecting mental retardation services.¹

¹The Developmental Disabilities Services and Facilities Construction Act of 1970 (P. L. 91-517). Mandatory that one third of each State Planning and Advisory Council be comprised of consumers.

The prevailing concept of care for the mentally retarded calls for the provision of services according to the needs of the individual at a given period in life. The continuum of care objective for the mentally retarded is reflected in the report of the President's Panel on Mental Retardation,² the comprehensive planning endeavors of individual states, and the social action programs being undertaken by local communities. Day care centers, diagnostic and evaluation clinics, preschool classes, recreational programs, sheltered workshops, and residential facilities are examples of some of the programs in operation at the community level in many states today. This is in contrast to ten years ago when care and treatment of the mentally retarded constituted early placement in a custodial institution or confinement to the privacy of the home.

TERMINOLOGY AND CLASSIFICATION OF MENTAL RETARDATION

Because the condition of mental retardation covers such a broad range of social functioning, it is less than simple to pinpoint either a uniform client group or a consistent pattern of intervention. To the physician, retardation may be viewed as a multiplicity of organic symptoms necessitating a program of medical intervention; the educator, orientated to the academic setting, may see the problem as poor capacity for learning. To the psychologist, it may present

²The President's Panel on Mental Retardation, "National Action to Combat Mental Retardation," October, 1962, U. S. Government Printing Office, Washington, D. C.

itself as problems of defective intellectual equipment and behavioral anomalies; while the social worker may be concerned about environmental influences. The administrator, in turn, may well be viewing treatment modalities in terms of finance, manpower needs, setting of priorities, and coordination of services.

All interpretations are, in a sense, valid in their own way and represent separate facets of a single phenomenon. However, in order to encompass these diverse features within a single framework, it is necessary to establish a workable definition of retardation which will prescribe its essential characteristics within manageable limits and still provide scope for its wider implications.

The most concise definition, and one which finds common acceptance in the United States, was advanced by the American Association on Mental Deficiency in 1959 and revised in 1961.³

Retardation is described as "subaverage general intellectual functioning which originates during the developmental period and is associated with impaired adaptive behavior."

In this definition, "subaverage general intellectual functioning" refers to all those who fall one standard deviation from the mean, below 85 I.Q. The term (subaverage general intellectual functioning) conceptualizes intelligence as a measurable human trait expressed as an I.Q. score which is distributed along a continuum, in

³Heber, R. F., "A Manual on Terminology and Classification in Mental Retardation," American Journal of Mental Deficiency, Monograph supplement (revised edition), 1961.

a "normal" distribution around a midpoint known as the average or mean, 100 I.Q.

An important property of the "normal" curve is that the theoretical distribution of I.Q. scores can be predicted statistically. Thus, about 16 per cent of the total population falls below one standard deviation from the mean, and about 3 per cent of the total population falls two standard deviations from the mean. If one assumes that one standard deviation is equivalent to 15 I.Q. points, this would suggest that about 16 per cent (32,000,000 persons out of a population of 200,000,000) have I.Q. scores below 85, and about 3 per cent (6,000,000 persons out of a population of 200,000,000) have I.Q. scores below 70.

It is noteworthy that in 1973, the American Association on Mental Deficiency saw fit to revise and modify this definition of mental retardation.⁴

The updated definition states that, "mental retardation refers to significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior, and manifested during the developmental period."

The revised manual stipulates that "significantly subaverage general intellectual functioning" refers to all those who fall two standard deviations below the mean, i.e., below 70 I.Q. Thus, a major

⁴Grossman, H. J., Manual in Terminology and Classification in Mental Retardation, American Association on Mental Deficiency, Special Publication Series No. 2, 1973 (Rev.).

segment of the population (26,000,000 persons out of a population of 200,000,000) with I.Q. scores between 70 and 85 who were formerly categorized as "Borderline Retarded" are now, by administrative decision, no longer considered to be mentally retarded.

A second essential and new condition to the classification of mental retardation in the revised A.A.M.D. definition pertains to the "concurrency" of deficits. Namely, an individual must manifest deficiencies in both adaptive behavior and intellectual functioning before being classified as mentally retarded. Perhaps the most important implication of this portion of the revised definition is that adaptive behavior can be modified. While it may not be possible to substantially improve the mentally retarded individual's intellectual ability, it has been amply demonstrated⁵ that his behavior in adjusting to his environment can be substantially improved through learning appropriate skills and knowledges, and through developing an improved self-image.

In essence, the revised definition places much emphasis upon the behavioral level of functioning of the individual. It considers his ability to solve problems presented by the environment and to conform to the standards of behavioral performance demanded by society. Within this framework, an individual may meet the criteria of mental retardation at one time in life and not at some other time. Whether or

⁵Katz, Elias, The Retarded Adult in the Community, Springfield, Ill., Charles C. Thomas, 1968.

not a person should be designated as mentally retarded would depend not just on measured intelligence, but also on the second criterion of the definition of mental retardation, "a distinct impairment of adaptive behavior."

In this context, the concept of mental retardation as a static and fundamentally irremediable condition would no longer be valid. Thus, a person who scored 65 on an intelligence test but who, at the same time, showed himself to be well able to adapt to the social demands of his particular environment at home, at work, and in the community would not be considered retarded.

Still, it is only recently that society has shown some willingness to consider alternatives to the isolated state residential institution as the main resource for the care and treatment of those deviant individuals labeled mentally retarded.⁶

ORGANIZATION OF THE STUDY

The purpose of this study is to identify those major factors that significantly affected public opinion, policies, and treatment patterns regarding the mentally retarded and, in turn, how these contingencies affected the development of community services for the mentally retarded in a major metropolitan city, Houston, Texas.

⁶President's Committee on Mental Retardation, "MR68 - The Edge of Change," Superintendent of Documents, U. S. Government Printing Office, Washington, D. C., 1968.

Specifically, the study will:

1. Through a comprehensive review of the literature, determine the effect social attitudes had upon the treatment modalities for the retarded.
2. Determine the effect Federal and state legislation has had upon the development of local community services for the retarded.
3. Identify the factors that are vital to the community planning process so as to insure maximum effectiveness of service delivery systems to the retarded.
4. Describe and propose the essential elements of a community program for the retarded so as to diminish levels of disability and maximize opportunities for normal community involvement.
5. Determine what organized efforts are necessary so as to enlist the cooperation of all existing social institutions, facilities, and services on behalf of the mentally retarded and their families.

CHAPTER II

AN HISTORIAL OVERVIEW OF SERVICES TO THE MENTALLY RETARDED

INTRODUCTION

The quality and degree of concern that any society demonstrates toward a handicap, whether it is due to an individual's disability or to a more endemic disease, seem to be determined by two major factors. They are: (1) the level of specialized knowledge which makes it possible to identify the nature of the handicap or social problem; and (2) the level of social development achieved by that society, particularly as this is reflected in the climate of opinion regarding the vulnerable and weak. Depending on the predominant social values, the attitude toward a handicap may be one of compassionate concern for its adverse impact upon the lives of the afflicted and a desire to avert or assuage these ill effects; or it may be an overwhelming fear that the socially adverse by-products of the handicap constitute a threat to the rest of society.¹ Both of these reasons bring the handicap into social prominence, and measures may be initiated to deal with either of them.

Illustrations of each of these points of view can be readily identified with the evolution of care and treatment of the mentally

¹Adams, M., Mental Retardation and Its Social Dimensions, New York: Columbia University Press, 1971, p. 16.

retarded in the United States. Parenthetically, it has been stated that the record of concern and care for the mentally retarded represents one of the most pathetic chapters in the history of man; a veritable black mark against humanity.²

In the beginning, the pioneering founders and supporters of institutions for the retarded were motivated by the desire to provide a regime of humane treatment for children with basic sensory defects. Later, imperceptibly at first, but then louder and louder, a cry of alarm was heard. The mentally defectives were a menace to society and society needed to be protected from the harm done by their presence in the community. Institutions, once envisioned as centers of "treatment," now became permanent places of segregation.

What caused this drastic change to take place? This chapter will serve to illuminate the different social philosophies underlying the successive patterns of care for the retarded, as they evolved in the United States, so they might be understood in the context of the trends now emerging and that will dominate the future scene.

THE EIGHTEENTH CENTURY - BEGINNINGS OF CARE

From the thirteenth century on, and prior to 1800, the churches of Europe began rather systematically to provide asylums for the mentally retarded. However, these "asylums" were intended solely to

²Baumeister, A. & Butterfield, E., Residential Facilities for the Mentally Retarded, Chicago, Ill. Aldine Publishing Co., 1970, p. 8.

provide a sanctuary for those unable to survive in a cruel, competitive society. No attempt was made at treatment or education. The prevailing belief during this period held that heredity was the primary cause of mental deficiency.

The substantive investigations of Cranefield (Cranefield, 1961, 1962, 1963) give evidence of the apparent lack of any systematic attempts to provide treatment for the mentally retarded. He indicates that the first "medical" treatise devoted solely to mental deficiency was written by a Swiss doctor named Paracelsus in 1530.³ He is one of the first writers to face the genetic problem by asking, "How it is that wise men may beget fools and that fools may beget wise men."⁴ The most remarkable discussion of mental deficiency in the seventeenth century, Cranefield contends, is that given in a paper written by Thomas Willis in 1672.⁵ In it, Willis also touches on the genetic concept and states that there are families in which "reckoning many descents backward, there is scarce one witty or wise man found." He also touched on the treatment aspects of mental deficiency. He said that the combined efforts of the physician and the teacher may help, but that if there were no improvements, further efforts would be in vain.⁶

³Cranefield, P., "Historical Perspectives," in Prevention and Treatment of Mental Retardation, Philips, I. (Ed.), New York, Basic Books, 1966, p. 3.

⁴Ibid., p. 4.

⁵Ibid., pp. 5-6.

⁶Ibid., p. 7.

As such, the condition was thought to be incurable and thus precluded any consideration of treatment or education. The concept held was "once retarded, always retarded," and, in retrospect, the mentally retarded were punished or largely ignored. At any rate, prior to 1800, the retarded did not come within the social arena of human concern.

At the close of the eighteenth century an event occurred which was destined to heavily influence the course of education for the retarded in later years. In 1798, some hunters chanced upon a twelve-year-old boy, naked, untrained, and inarticulate, who had been living in the forest of Aveyron, France. The boy manifested the traits of a completely unsocialized being. He walked on all fours, responded to human overtures with biting and scratching, and displayed habits of eating, drinking, and elimination like those of an animal.⁷

Jean Itard, a physician, took charge of the boy who was subsequently named Victor. Itard had been influenced by the teachings of John Locke of England and Jean Rousseau of France who believed that learning came only through the senses and that all persons could develop the ability to learn if given adequate stimulation. From this perspective, Itard mounted an intensive effort to educate and train Victor. His therapeutic program included sustained periods of individualized attention with heavy emphasis on sensory, social and motor stimulation.

⁷Kanner, L., A History of the Care and Treatment of the Mentally Retarded, Springfield, Ill.; Charles C. Thomas, 1964, pp. 12-16.

While his efforts resulted in many marked behavioral changes in Victor, Itard was unable to teach him to talk or to live independently in Parisian society. After five years of intensive work, Itard considered his experiment a failure and discontinued his program of training. Although Itard failed to achieve the goals with Victor which he had set forth for himself, his work represented the first scientific attempt at training a retarded child. It marked a radical change of emphasis from the notion of incurability and isolation to treatment and education. Further, it demonstrated that special techniques could be effective in modifying the behavior of rather low-functioning individuals even if they did not alter fundamentally the underlying defective condition. Indeed, Itard's efforts established the foundation for a whole new philosophy of treatment which would have great impact on the retarded during the nineteenth century and subsequently become the basis of educational programs established by Edward Seguin and later by Maria Montessori.⁸

THE NINETEENTH CENTURY - DEVELOPMENT OF INSTITUTIONS

Some years after the conclusion of Itard's project, a former student of his, Edward Seguin, undertook a similar task of educating an idiot boy using a complex, systematic sequence of training which he called the "physiological method."⁹

⁸Crane, P., Op. Cit., pp. 9-10.

⁹Talbot, Mabel E., Edward Seguin: A Study of an Educational Approach to the Treatment of Mentally Defective Children, New York: Bureau of Publications, Teachers College, Columbia University, 1964.

After a year's work, and in the face of considerable skepticism by his professional colleagues, Seguin reported his results to a commission from the Academy of Science in Paris. His apparent success in this new and allegedly hopeless field resulted in an official appointment to the two pauper hospitals in Paris--Bicetre and the Hospice des Incurables. Working with children who resided in the "idiots" section of these hospitals, Seguin began to develop his unique educational methods on a wider scale than ever before attempted.

His primary goal, to raise the individual's limited capacity to its full potential by specially devised methods, was in contrast to the attempts of others who sought to restore a retarded individual to normal functioning. In fact, he seems to have been the first person to accept the defects of the retarded realistically and at the same time maintain an optimistic belief in their capacity for improvement if given appropriate help. The evident success that Seguin achieved with his idiot pupils brought him immediate recognition and, in 1846 when he published his classical textbook, The Moral Treatment, Hygiene and Education of Idiots and Other Backward Children, his fame spread far and wide, and he was recognized as an international figure in the field of mental retardation.¹⁰ The extensive materials subsequently published by Seguin became the basis of scientific literature on the psychological characteristics and educational potential of the mentally handicapped.

¹⁰Kanner, Op. Cit., pp. 35-36.

Prior to the nineteenth century, there was no public or private facility for the care of retarded children on the North American Continent.¹¹ A small attempt was made in 1818 to provide a place for a very limited number at the Asylum for the Deaf and Dumb in Hartford, Connecticut. However, the increasing interest in the rehabilitation of children with sensory handicaps, such as blindness and deaf-mutism, was leading physicians in America to consider the related condition of mental deficiency. In 1848, Dr. Henry Wilbur, inspired by the work of Seguin in Paris, took into his home at Barre, Massachusetts, a group of mentally defective children and opened the first private school for defective boys in the United States.

At about the same time Dr. Samuel Gridley Howe, then director of the Perkins Institution for the Blind in Boston, who had a profound interest in the feeble-minded, undertook the task of convincing the Massachusetts legislature that the training and education of the feeble-minded was a public responsibility. Upon his urging, the Legislature consented to allow \$2,500 per annum for three years for the teaching and training of ten idiotic children on an experimental basis at the Perkins Institution.¹²

It is significant that the establishment of this program with state funds constituted the first sign of public concern for the feeble-minded in the United States. Subsequently, in 1855, the

¹¹ibid., pp. 38-39.

¹²ibid., pp. 42-43.

Legislature established the Massachusetts School for Idiotic and Feeble-Minded Youth in South Boston and, in 1887 located it permanently in Waltham, Massachusetts. It is now known as the Walter E. Fernald State School, in recognition of one of its most distinguished superintendents.

During the same period of time (1850), Edward Seguin decided to emigrate to America for political reasons and added his knowledge and genius to the residential programs developing in the United States. At the invitation of Samuel Howe he established the basic program at the school in South Boston. For a brief time he was head of the Pennsylvania Training School for Idiots. He played a major role as consultant to all who were interested in establishing new residential treatment facilities for retarded children or improving those already in existence. As United States Commissioner of Education, he published a comprehensive report on child rearing, school education, and the care of handicapped children. In 1876, he was chosen as the first president of the organization which is known today as the American Association on Mental Deficiency.

Following the steps taken by Massachusetts and inspired by the methods of Seguin, other states began to take action. New York opened a school at Albany in 1851, Pennsylvania in 1852, and Ohio in 1857. The movement gathered steam, and by the turn of the century nineteen states had set up twenty-four institutions for retarded children. The outstanding accomplishments and success which Seguin demonstrated in particular cases of retardation resulted in a philosophy of unrestrained optimism. All the institutions had flourishing and forward-looking programs, which emphasized education

and training. They were begun as "experimental laboratories" to test Seguin's methods and the effects of environment on retardation.

The formation of the Association of Medical Officers of American Institutions for Idiotic and Feeble-Minded Persons in 1876 (presently the American Association on Mental Deficiency) provided a forum for the exchange of ideas and knowledge at its annual meetings. These reports presented at the Association's annual meetings suggest that the standards of care in the institutions were of very high quality. A report from California (1888) refers to "the wonderful physical and very pleasing mental improvement of most of the inmates which is accounted for very largely by the care we have bestowed upon their meals, bathing, and beds." A description of the grounds mentions "palms, roses, pepper trees, and other subtropical plants which ornament the grounds and tend to gladden the eyes of children and quicken their sluggish brains to thought."¹³ This observation reflects a genuinely compassionate and imaginative approach to the retarded as well as optimism in their capacity to react favorably to good surroundings and material care.

The state institutions of this period were intended as training schools and not asylums. The motivating belief was that most all the mentally deficient could be "cured" through education and training and returned to the community as average citizens. A premise not unlike that, and perhaps equally as naive, is espoused by many professional workers in the field today.

¹³Kerlin, J. N., in Proceedings of the Association of Medical Officers of American Institutions for Idiotic and Feeble-Minded Persons, Nos. 11-19 (1888), pp. 65-67.

The Pennsylvania Training School started a kindergarten class because it was felt that early training was very important. "From the early hand-training to which these little juniors are submitted we shall have finer capacities in the future for our industrial classes and our work will be much superior to the past."¹⁴

The Training School in Frankfort, Kentucky, introduced industrial training between 1878 and 1879. The purpose was to prepare the residents for economic independence after their ten-year period of institutional care. Boys were employed in carpentry, shoemaking, mattress, broom, and mop making; and the girls in sewing, cooking, laundry, and kitchen work. These training units were considered to be self-supporting by virtue of the maintenance services they rendered to the institution. By 1888, out of a total of 150 residents, 80 were receiving industrial training. Over the ten-year period, 39 had been placed satisfactorily.¹⁵

Industrial training was quickly incorporated into most of the institutions' programs by 1885. The original objective of educating those who were potentially able to return to normal life within the community had emerged as a new facet of industrial rehabilitation. On the whole a good start seems to have been made.

It is evident that during this period, as residential treatment facilities for the mentally handicapped were evolving in the United States, certain features of the social history of the time were being

¹⁴Ibid., J. N. Kerlin in, p. 166.

¹⁵Ibid., J. Stewart in, pp. 54-56.

reflected. Both the old and the new worlds were imbued with a strong element of idealistic thinking which embraced deep concern for the suffering and welfare of the down-trodden and socially disadvantaged.¹⁶ Freedom in its various aspects was a recurring motif of the time. It was not accidental that Samuel Howe and his family were ardent champions of Negro emancipation (his wife, Julia Ward Howe, wrote the "Battle Hymn of the Republic"),¹⁷ that Seguin came to America because of disillusionment with the political regime in France, and that in Massachusetts, where the residential movement for the care of the retarded began, the cultured, humanitarian group formed by Thoreau, Emerson, and their extensive following was spreading in influence.¹⁸

The climate of hope generated by these exciting trends embraced the mentally retarded too, so that in the twenty-five years from 1848 to 1873, eight states in America had set up humanitarian rehabilitation programs for a handicap that had hitherto been recognized only as a life sentence of hopelessness.

Unfortunately, these dedicated and progressive efforts were doomed to fall short of their aspirations and by the 1880's the dream of the institution as an educational center began to evaporate.

The founders of the first residential institutions set forth as their purpose the treatment of mental deficiency with a view toward

¹⁶Kanner, Op. Cit., pp. 83-86.

¹⁷Haskell, R. H., "The American Movement in Mental Deficiency: An Apostrophe to the Memory of a Noble American," American Journal of Mental Deficiency, No. 3, January, 1945.

¹⁸Brooks, Van Wyck, The Flowering of New England, New York: Dutton Co., 1936, p. 108.

returning them to the community--a community, to be sure, less complex than today's. The early literature is replete with statements reflecting an uncritical and overriding faith in the efficacy of the physiological method.¹⁹ Mental deficiency was regarded basically as a lag of the development of intelligence. With proper diligence and skill, the mind could be trained. Moreover, there were many favorable reports of the wonders that the early institutions worked on their students. The "model" school in Massachusetts issued a report which declared that the "popular air that idiocy is a positive incurable malady had been disproved." In one report after another, in state after state, the conviction was expressed, often in glowing language, that access had been gained to the brain of the retarded. It was indeed a period of altruism and hope.

But the accomplishments could not match the hope. As the industrial revolution took hold in America, accompanied by the complexities of urbanization, a vast array of social pathology resulted from the rapid and severe dislocations in patterns of living. The impact of these drastic changes in social conditions was soon felt by the retardate returning to the community from the institution.

It soon became clear that the young retarded adult was not able to cope with the harsh and chaotic social conditions prevailing outside of the institution, no matter how well trained in domestic

¹⁹Barr, M., Mental Defectives: Their History, Treatment, & Training, Philadelphia, P. Blakiston's Son & Co., 1913.

or other work. In addition, because of the devastating social forces that were dislocating so many people's lives, most of the children admitted to institutions came from very poor families whose poverty or social dysfunctioning made them unable or unsuited to assume responsibility for supervision or care of their child being returned to the community.²⁰

Moreover, the acceptance of institutions by the general public, as centers of treatment, education and training, was something short of overwhelming. As evidence began to accumulate to show that many of the early claims to success were ill-founded, the public became convinced that not much, if anything, could be done to benefit the retarded. Consequently it was argued that expenditures of funds for institutions might well be put to more constructive purposes. In 1857, the Governor of Massachusetts justified his veto of a bill to increase the state institution allocation by the statement: "When the State shall have sufficiently educated every bright child within its borders, it will be time enough to undertake the education of idiots and feeble-minded children."²¹

The utmost needs of the retarded were soon to be a constant source of concern to the institution personnel who frequently found themselves wondering in which direction their professional and social

²⁰Stewart, J., in Proceedings of the Association of Medical Officers of American Institutions for Idiotic and Feeble-Minded Persons, No. 1-10, 1882, pp. 238-239.

²¹Best, H., Public Provision for the Mentally Retarded in the United States, Worcester, Massachusetts, Hefferman Press, 1965, pp. 8-9.

obligations lay. In 1888 the director of Elwyn Institute in Pennsylvania formulated his new policy in the following statement:

With the appalling numbers of applicants for admission and from a conviction that the State will not burden taxpayers with the support of more than a fraction of those needing it, it becomes imperative for us to devise economical methods by which a moderate good shall be done for the greatest number.²²

Thus, by the last quarter of the nineteenth century, as the chaotic state of social change continued, and as more of the mentally retarded failed in an unstable and unsympathetic environment, it became obvious that rehabilitation into the community was not a feasible plan for the retarded.

The dream of the institution as an educational facility began to evaporate. As problems arose and were identified in the community, the institutions were looked upon as the inevitable and terminal solution. Those in charge of institutions were made to realize, and soon came to believe, that their functions must be extended beyond relatively short-term training to include comprehensive care for the retarded individual for long periods of time--even a lifetime. Yet the rationale espoused for this new development of long-term custodial care was still based upon a humane desire to help the retarded. It was perceived as a step to provide them with a protective environment which would allow them to utilize their skills and to live happily with their "own kind."

²²Kerlin, I., Op. Cit., p. 166.

It is enlightening to note that as the attitudes of professionals in the field began to change, so too did the physical aspects of institutions. By 1875, there was a strong trend toward the construction of more and larger institutions whose role was more frankly conceived as custodial in nature. A number of states began to plan and build such types of institutions. Moreover, with the abandonment of the concept of cure, the nature of the institution, both in service and in its physical plant, began to change. By the end of the nineteenth century the now familiar large isolated residential institution began to emerge on the landscape of America. Each with well-diversified Gothic buildings, highly organized custodial staffs, and its own social structure, wherein the long-term residents were helped to develop their abilities and to put them to some practical use, thereby insured its continued maintenance.

M. W. Barr, writing in the Journal of Psycho-Asthenics in 1899, expressed the new sentiment by noting that experience and indeed every consideration for the individual and society, points to the absolute necessity of permanent segregation.²³

A year later, Dr. A. Johnson wrote that "...the proportion of feeble-minded who are fit to go out from our schools to take a place in the great world, with all that implies, is so small that it may be safely disregarded in adopting a policy." "The retarded," he explained,

²³Barr, M. W., "The How, the Why, and the Wherefore of the Training of Feeble-Minded Children," Journal of Psycho-Asthenics, 1899, 4, pp. 204-212.

"must be kept quietly, safely, away from the world, living like angels in Heaven, neither marrying nor given in marriage."²⁴

It is significant to note that by the end of the nineteenth century, care and treatment patterns for the mentally retarded had shifted from a strong element of idealistic thinking, which embraced a therapeutic regime of rehabilitation and self-determination, to a paternalistic system of custodial care which, while protective in nature, embodied the concept of deprivation of individual liberty as a major premise.

THE TWENTIETH CENTURY

CUSTODIAL CARE VS. COMMUNITY LIVING

At the dawn of the twentieth century a new development took place which was to plunge the treatment modalities for the mentally retarded into a dark and forlorn era from which we are only now beginning to emerge.

During the early years of this century, two important events took place which served to cause society to become greatly alarmed by the presence of the mentally retarded in their midst. These events were the "eugenics scare" that began early in the century and the coincidental development of intelligence testing in the United States. Together, they exerted a tremendous influence upon society's perception of the retardate and the ensuing modes of treatment.

²⁴Johnson, A., "The Self-Supporting Imbecile," Journal of Psycho-Asthenics, 1900, 4, pp. 91-100.

The eugenics movement owes its original impetus to Sir Francis Galton who, in 1865, expressed his concern about the destiny of the human race with the proposition that unchecked fertility of the unfit was a threat to be averted by specific programs calculated to reduce their birth rate. In 1883 he introduced the concept of eugenics as "the Science which deals with all influences that improve the inborn qualities of a race."²⁵

Eugenics played an important role in shaping American attitudes about the solution of many social problems, and particularly the problem of mental retardation. Charles Davenport, one of the first American proponents of eugenics described it as "...the science of the improvement of the human race by better breeding (1911)."²⁶ The fundamental idea being that to create a better breed of people, those with desirable traits must be encouraged to propagate, and those with undesirable traits should not be permitted to propagate. It followed, therefore, that since the mental retardate possessed undesirable traits he should not be allowed to reproduce.

Attention was drawn to the recurrence of certain patterns of sociopathic behavior within identified families and kinship groups which suggested that these undesirable tendencies were of an inherited nature. In addition, the association of low mentality with many of these other traits among these families (the Jukes, the Killikaks, the Pinneys) gave impetus to the idea that low intelligence was

²⁵Kanner, L., Op. Cit., p. 128.

²⁶Davenport, C. B., Heredity in Relation to Eugenics, New York: Henry Holt and Co., 1911.

genetically determined and was the constant factor underlying, and responsible for, all the other symptoms of social failure.²⁷

Consequently, social control of the feeble-minded, who were feared to be waiting in untold numbers to prey on society with their destructive patterns of life, became the dominant treatment theme of the early nineteenth century. Attempts to implement control were expressed in legislation for sterilization and in the proposal to extend custodial care to cover all the retarded in the nation during their childbearing period if not for life.²⁸

Coincidentally, the impact of Binet's methods of measuring intelligence began to be felt in America. Dr. Henry H. Goddard, then director of the Research Laboratory at the Training School at Vineland, New Jersey, showed great interest in Binet's tests and, with modifications, applied them to thousands of children in the United States. Not only did these tests provide a rapid and systematic means of measuring intellectual capabilities, but they also were responsible for bringing to light a very large group of persons of borderline intelligence who were hitherto largely unrecognized as retarded. They were individuals whose intelligence quotients registered above the upper level of the "imbecile" group and below what was considered to be the lower level of normal intelligence. To designate this class of high grade and borderline mental defectives, Dr. Goddard introduced

²⁷Adams, M., Op. Cit., p. 30.

²⁸Davies, S., The Mentally Retarded in Society, New York: Columbia University Press, 1959, pp. 45-46.

the term "moron," from the Greek word meaning "foolish," in 1910.²⁹

At the time he stated:

I presume no one in this audience, certainly none of the superintendents of institutions, need to be reminded that the public is entirely ignorant of this particular group. Our public school systems are full of them, and yet superintendents and boards of education are struggling to make normal people out of them. One of the most helpful things that we can do would be to distinctly mark out the limits of this class and help the general public to understand that they are a special group and require special treatment, in institutions when possible, in special classes in public school when institutions are out of reach.³⁰

It is significant that sixty-three years later, in 1973, the American Association on Mental Deficiency issued a revised and modified definition of mental retardation wherein this borderline group was no longer classified as mentally retarded and thereby excluded from special education programs.³¹ Could it be that the label "mental retardation" has more to do with social-political events rather than with biological-psychological-scientific matters?

During the early years of the twentieth century, the many manifestations of the severe social pathology and dislocation of the times, (pauperism, vagrancy, alcoholism, and delinquency), lumped together under the heading of "moral degeneracy," drew attention to the many individuals in society who were functioning at a "socially"

²⁹Ibid., pp. 28-31.

³⁰Kanner, L., Op. Cit., p. 123.

³¹Grossman, H. J., Op. Cit.

subnormal level.³² Studies and proclamations were not long in following that would subtly develop the image of the retardate as a social menace. Heredity and feeble-mindedness were shown to be closely related. More than that, various forms of degeneracy and feeble-mindedness were even more closely connected.

As time passed, the social indictment of the retardate grew more direct, severe, and shrill. Some of the major indictors were the then leaders in the field of mental retardation. Many had been, or became, presidents of what is now the American Association on Mental Deficiency.

Walter E. Fernald, then superintendent of the Fernald State School in Waltham, Massachusetts, and one of the most influential men of the time, summarized the trend as follows:

The intensive studies of the family histories of large numbers of the feeble-minded by Goddard, Davenport, and Tredgold have demonstrated what had hitherto only been suspected, that the great majority of these persons are feeble-minded because they come from family stocks which transmit feeble-mindedness from generation to generation in accordance with the laws of heredity. The number of persons who are feeble-minded as a result of injury, disease, and other environmental conditions without heredity dispositions is much smaller than had been suspected...

He continued:

The cumulative evidence furnished by surveys, community studies, and intensive group inquiries have now definitely proved that feeble-mindedness is an important factor as a cause of juvenile vice and delinquency, adult crime, sex immorality, the spread of venereal disease, prostitution, illegitimacy, vagrancy, pauperism, and other forms of social evil and social disease...

³²Adams, M., Op. Cit., p. 30.

He went on to state that:

...there are reasons for believing that feeble-mindedness is on the increase, that it has leaped its barriers, so to speak, as a result of changed conditions of civilization.³³

Goddard, another leader in the field stated:

For many generations we have recognized and pitied the idiot. Of late we have recognized a higher type of defective, the moron, and have discovered that he is a burden; that he is a menace to society and civilization; that he is responsible to a larger degree for many, if not all, of our social problems.³⁴

Retarded women were looked upon as being even more dangerous than men. Fernald stated that:

Feeble-minded women are almost invariably immoral, and if at large, usually become carriers of venereal disease, or give birth to children who are as defective as themselves. The feeble-minded woman who marries is twice as prolific as the normal woman.³⁵

Notes of an ominous and even menacing nature were being sounded. Alexander Johnson, past president of the National Conference of Charities and Corrections, and one of the most influential figures in the social action field of that era stated: "I do not think that, to

³³Fernald, W. E., "What is Practical in the Way of Prevention of Mental Defect," Proceedings, National Conference of Charities and Corrections, 1915, in Changing Patterns in Residential Services for the Mentally Retarded, A President's Committee on Mental Retardation Monograph, Washington, D. C., 1969, pp. 289-297.

³⁴Goddard, H. H., "The Possibilities of Research As Applied to the Prevention of Feeble-Mindedness," in Changing Patterns in Residential Services for the Mentally Retarded, A President's Committee on Mental Retardation Monograph, Washington, D. C., 1969, pp. 307-312.

³⁵Fernald, W. E., Op. Cit., pp. 90-91.

prevent the propagation of this class (the retarded), it is necessary to kill them off or to resort to the knife; but, if it is necessary, it should be done."³⁶

Another professional, L. C. Streeter, said that: "...In feeble-mindedness lies the tap root of most of our social problems; the only effective radical way to deal with these problems, is to strike at this tap root with the strong ax of prevention."³⁷

The peak of the social indictment of the retardate was realized between 1908 and 1915 and resulted in two significant forms of social action for coping with this problem.

1. Segregation of all retarded persons from society.
2. Sterilization of all female retardates.

As the notion took hold that the mentally retarded would soon overpopulate our land, a concerted effort was made to remove these persons as far from society as possible. In the first half of the present century there was a huge surge toward the building of institutions. In 1890 approximately 20 residential schools for the retarded had been established in 15 states. By 1968 there were 167 public residential facilities for the mentally retarded in the 50 states and the District of Columbia.

In 1890 the residential population consisted of several thousand persons. In 1903, before the beginning of general public agitation, the

³⁶Johnson, A., "Discussion on Care of Feeble-Minded and Epileptic," Journal of Psycho-Asthenics, 1901, pp. 410-411.

³⁷Streeter, L. C., Proceedings, National Conference of Charities and Correcations, 1915, Changing Patterns in Residential Services for the Mentally Retarded, A President's Committee on Mental Retardation Monograph, Washington, D. C., 1969, pp. 340-352.

number of persons in institutions for the retarded was approximately 14,500.. In the following twenty years (1903-1923), during which time the most active propaganda for increased institutional accommodations was carried on, the institutional population for the retarded had grown to approximately 43,000. By 1956, more than 107,000 persons were residing in institutions for the retarded, and by 1972 there were more than 200,000 retarded individuals in public institutions.^{38,39}

Institutions grew larger. They became more custodial rather than educational. They endeavored to become self-sustaining and to manage as economically as possible. Various forms of "institutional peonage," rationalized under the guise of "training" programs, developed out of problems of severe underfinancing.

The trend toward a penurious fiscal attitude was evident by the statement of Fernald that: "When the feeble-minded are recognized in childhood and trained properly, many of them are capable of being supported at low cost under state supervision."⁴⁰

The growing rationalization for exploitation of residents was made apparent when Johnson stated:

The only hope that I can see of the state taking complete care and responsibility of all idiots and imbeciles is that all

³⁸Davies, S. P., Op. Cit., pp. 69-70.

³⁹Rosen, D. and Callan, L., A Report of Trends in Residential Services for the Mentally Retarded, Arlington, Virginia: National Association of Superintendents of Public Residential Facilities, 1972, p. 17.

⁴⁰Fernald, W. E., "A State Program for the Care of the Mentally Defective," Mental Hygiene, 1919, Vol. 3, pp. 566-574.

those who have been trained, those of the higher grade who are susceptible to training, ...shall be so usefully employed that they may be practically self-supporting. We used a great deal of labor... ...in the care of the lowest custodial grade of imbeciles, in the care of epileptics of low grade... ...and they can do no better work than to exercise such care in an institution.⁴¹

Residents were worked to the limit of their capacity, and, it appears, sometimes even beyond. Superintendent J. M. Mastin stated his viewpoint thusly:

Heartbreaking and unprofitable work for normal persons would be particularly fitted and agreeable, if not joyful occupation for retardates. If they work them as hard as they can, they will not practice the vices...let them go out and work just as hard as they will work. That is what they have to do for me when they work on the farm. They work so that when they come in at night they go to bed and sleep. Then they get up the next morning and go to work again...⁴²

Stripping the retardate's environment of amenities and comforts so as to cut costs accompanied by righteous rationalizations was made evident by a further statement of Mastin:

As a rule, mental defectives are descended from the poorer classes, and for generations their people have lived in houses having few conveniences. To expect them to be content in a great city institution with its up-to-date furnishings and equipment is unreasonable. They find little comfort in steam heat and polished floors; and the glare of electric lights too often adds to their restlessness.⁴³

⁴¹Johnson, A., "Custodial Care," Proceedings, National Conference of Charities and Corrections, 1908, in Changing Patterns in Residential Services for the Mentally Retarded, A President's Committee on Mental Retardation Monograph, Washington, D. C., 1969, pp. 333-336.

⁴²Mastin, J. T., "The New Colony Plan for the Feeble-Minded," Journal of Psycho-Asthenics, 1916, Vol. 21, pp. 25-35.

⁴³ibid., p. 38.

Thus, by the first quarter of this century, institutions for the retarded had become purgatories instead of the "places of paradise" envisioned by the leaders of the institutional movement during the nineteenth century. Only since World War II, and particularly in the past decade, have the professional community and the public begun to question the traditional institutional model. Today the emphasis seems to be shifting to systems of short-term care with emphasis upon scientifically based programs designed to assist the individual retardate toward better behavioral adjustment.

However, the pace is slow and the millennium is still a long way off. Too many large and bleak wards are still in existence, and too many individuals still receive only minimal care. One has only to read of the relatively recent visits to state institutions for the mentally retarded as described by Dr. Burton Blatt (Christmas in Purgatory: a Photographic Essay on Mental Retardation, Boston: Allyn and Bacon, 1967), to be shocked into an awareness of how far away we still remain from the millennium.

To quote Blatt:

Many dormitories for the severely and moderately retarded ambulatory residents have solitary confinement cells or, what is officially referred to and is jokingly called by many attendants, "therapeutic isolation." "Therapeutic isolation" means solitary confinement, in its worst punitive and inhumane form.

Isolation cells are generally tiny rooms, approximately 7 feet by 7 feet, shielded from the outside with a very heavy metal door having either a fine strong screen or metal bars for observation of the "prisoner." Some cells have mattresses, others blankets, still others bare floors. None that I had seen (and I found these cells in each institution visited) had either a bed, a wash stand, or a toilet.

What I did find in one cell was a 13- or 14-year-old boy, nude, in a corner of a starkly bare room, lying on his own urine and feces. The boy had been in solitary confinement for several days for committing an institutional infraction, as I recall, directing abusive language to an attendant. Another child, in another institution, had been in solitary confinement for approximately 5 days for breaking windows.⁴⁴

Bengt Nirje, a professional worker for the retarded in Sweden, made the following observations (1969) upon visiting a number of public institutions in the United States:

In another and new building at institution No. 1, moderately retarded girls of ages 10 to 16 were housed. Most of these girls apparently attended a training program, but 40 of them slept in the same bedroom, and the huge day-room was equipped with only a few benches and a TV set. This created a deadening atmosphere for the girls upon their return from classes or recreation.

One superintendent told me about an institution in state "O" where a building for 180 moderately and severely mentally retarded males also had a fenced-in outdoor area. Ninety of these men were regularly led out to the fence, where they were attached with leather straps to the fence posts, their hands buckled to their waists with leather loops. They could move in a radius of only 24 inches, and along the fence there were a series of deep circles of that size.⁴⁵

Still more recently (1972), Geraldo Rivera, a television newsman, writes of his visit to Willowbrook State School in New York where 5,000 mentally retarded people reside:

When Dr. Williams slid back the heavy metal door of B Ward, building No. 6, the horrible smell of the place staggered me. It was so wretched that my first thought was

⁴⁴Blatt, B., Christmas in Purgatory: A Photographic Essay on Mental Retardation, Boston: Allyn and Bacon, 1967, p. 13.

⁴⁵Nirje, B., "A Scandanavian Visitor Looks at U. S. Institutions," Changing Patterns in Residential Services for the Mentally Retarded, A President's Committee on Mental Retardation Monograph, Washington, D. C., 1969, pp. 53-57.

that the air was poisonous and would kill me. I looked down to steady myself and I saw a freak: a grotesque caricature of a person lying under a sink on an incredibly filthy tile floor in an incredibly filthy bathroom. It was wearing trousers, but they were pulled down around the ankles. It was skinny. It was twisted. It was lying in its own feces. And it wasn't alone. Sitting next to this thing was another freak. In a parody of human emotion they were holding hands. They were making a noise. It was a wailing sound that I still hear and that I will never forget. I said out loud, but to nobody in particular, "My God, they're children."

Williams looked at me and said, "Welcome to Willowbrook."⁴⁶

In his charge to the members of the President's Committee on Mental Retardation (1972), President Nixon presented as a major goal, the return to the community of one-third of the more than 200,000 retarded individuals presently residing in public institutions; the current rate of discharge being less than ten per cent. Yet, in a recent survey (1972) made of public residential institutions for the mentally retarded, it was ascertained that 37 per cent of this population were in the mild and moderate classifications. Furthermore, a majority of the institutions had long waiting lists for admission.⁴⁷ The question needed to be asked is: Why are these 78,000 mild and moderate retarded persons not today living and being treated in their home communities?

Apparently social control of the retarded, who were feared to be waiting in untold numbers to prey on society with their destructive patterns of life, still remains the strong, if not dominant theme.

⁴⁶Rivera, G., Willowbrook: A Report on How It Is and Why It Doesn't Have to Be That Way, New York: Random House, 1972, p. 3.

⁴⁷Rosen, D. and Callan, L., Op. Cit., pp. 3-5.

And the earlier thrusts to implement this control, through the extension of institutional custodial care of all the retarded in the country during their childbearing period, if not for life, and in legislation for sterilization, are difficult to erase.

In 1907, beginning with Indiana, many states began to hurriedly pass sterilization laws. By 1926 sterilization statutes had been passed in 23 states. Many of these laws were motivated by therapeutic and punitive considerations. In 1927, the U. S. Supreme Court upheld the constitutionality of compulsory sterilization of retardates when Justice Holmes rendered his famous opinion: "Three generations of imbeciles are enough."⁴⁸ The whole issue of sterilization has undergone considerable discussion on moral, legal, and scientific grounds and is a subject of controversy even today.

The most recent survey indicates that in 1966 there were still 23 states with statutes providing for compulsory sterilization of mental retardates. In eight of these states, the statutes permit sterilization whether or not the person found retarded had been institutionalized. For the rest, sterilization laws applied only to institutionalized mental retardates. Although these laws are infrequently applied today in practice, (in 1943 compulsory sterilization operations had been performed on 1,643 retardates, and in 1963 there were 643 operations performed),⁴⁹ the prime targets for compulsory

⁴⁸Baumeister, A. and Butterfield, E., Op. Cit., p. 12.

⁴⁹Burt, R. A., "The Right to Marry and the Right to Choice Regarding Sterilization," in Advocacy for the Legal and Human Rights of the Mentally Retarded, Ann Arbor, Michigan, Institute for the Study of Mental Retardation and Retarded Disabilities, 1972, pp. 49-50.

sterilization appear to be those retardates who are being released from institutions. The Nebraska Supreme Court, in its 1968 opinion upholding the constitutionality of the state's compulsory sterilization law for institutionalized mental defectives, stated, without any evidence of empirical support: "It is an established fact that mental deficiency accelerates sexual impulses and any tendencies toward crime to a harmful degree." The Nebraska Legislature later repealed its compulsory sterilization law before the U. S. Supreme Court had the opportunity to rule on the constitutionality of this decree.⁵⁰

Robert A. Burt, Associate Professor of Law at the University of Michigan, speaking at the Advocacy Conference on the Legal and Human Rights of the Mentally Retarded, in Ann Arbor, Michigan, June, 1972, stated: "I believe the laws that single out mental retardates, or any stigmatized group, clearly identified as such, for special restrictions in sexual or family life violate the United States Constitution."⁵¹

Undoubtedly, the eugenics scare contributed heavily to the change in attitude of society toward the mentally retarded in the United States. Whereas the mid-nineteenth century saw the emergence of a compassionate approach, expressed in remedial plans for care of the retarded based on sound scientific principles, the twentieth century witnessed a very different concept of the retardates' role in society and their needs. The entire philosophic rationale underlying the pattern of services and its acceptance by society as a whole had shifted.

⁵⁰Ibid., p. 52.

⁵¹Ibid., p. 52.

The trend, in the twentieth century, was toward a gradual social devaluation of the retarded as human beings. Systematically they were physically and psychologically alienated from society in a manner that singled them out on a fundamentally negative basis and in a way that no other group had experienced since the quarantining of lepers in the Middle Ages.⁵²

History records that during these early years of the twentieth century and, indeed, even the latter part of the nineteenth century, efforts were being made, however slight, to develop systems of care of the retarded within the community. The specific factors that fostered, or hindered, their development will be investigated in later chapters. In order to maintain the historical continuum of services to the retarded; however, it is necessary to trace the evolution of these programs within this chapter.

The establishment of special educational facilities within the public school system, and the efforts to cope with the numerous requests for advice that the institutions were receiving, inevitably helped to lay the foundation for the development of community services for the mentally retarded.

Special classes were established in Providence, Rhode Island as early as 1896; and later in Springfield, Massachusetts; Chicago; Boston; New York; Philadelphia; Los Angeles; Detroit; Trenton, New Jersey; Washington, D. C.; Bridgeport, Connecticut, and Rochester, New York. By 1905, the idea of special classes in public schools had

⁵²Adams, M., Op. Cit., pp. 32-33.

pretty well taken hold and, in the same year the first training program for teachers of special classes was offered at the New Jersey Training School for Feeble-Minded Boys and Girls.⁵³

In 1891, a weekly diagnostic outpatient clinic was established at the Massachusetts State Training School and by 1920 the clinic had handled over 6,000 inquiries. This innovation was the start of effective community care because, in addition to offering a diagnostic evaluation, it also provided follow-up examinations and counseling. In 1915, at the request of the public school authorities, the scope of this clinical service was extended to include monthly diagnostic examinations for schools in the four leading cities within the institution's orbit.⁵⁴ Not unlike, incidentally, the "outreach" programs of today's state institutions.

Paralleling this move to provide care within the community, institutions were beginning to shift some of their residents back to the community through what was referred to as the "Parole Plan." Massachusetts took the lead in this venture, followed by New York and Pennsylvania.⁵⁵ Then, in 1919, Dr. Fernald published a paper on the status of all patients who had been paroled from the institutions between the period 1890-1915. His findings showed that not all the mentally retarded were unredeemably bad as had been feared, and that

⁵³Kanner, L., Op. Cit., p. 115

⁵⁴Fernald, W. E., "An Outpatient Clinic in Connection with a State Institution for the Feeble-Minded," Journal of Psycho-Asthenics, XXV, (1920-1921), pp. 81-89.

⁵⁵Davies, S. P., Op. Cit., pp. 153-160.

many showed a considerable potential for leading stable adult lives if given appropriate help. As parole developed all over the country, institution workers found themselves more and more in the role of job and home finders. Again, not unlike today's counterpart in community rehabilitation and social service agencies.

A second noteworthy program that developed during this era was the "Colony Plan," whereby the more capable retardates were given the opportunity for training in productive work away from the institution. It started with the acquisition of a series of abandoned farms in Massachusetts, New Jersey, and New York. Each farm was organized as a separate unit and managed by a farmer and his wife who trained and supervised groups of between 10 and 20 men. Later on, in 1914, similar ventures for girls were started. Large houses, in well-populated communities, were rented or purchased and small numbers of young women lived in them under the supervision of institution staff persons. The girls were employed during the day in factories or as domestics in private homes, and returned to the colony at night.⁵⁶

In effect, the colonies could be viewed as the prototype of the present day halfway houses that are in existence in most large metropolitan areas in the United States. Of course, the colonies afforded considerably less opportunity for independence and self-management on the part of the residents, than do today's halfway houses.

⁵⁶Ibid., pp. 121-137.

The next phase of community-oriented care was the development of a plan for "family" care. This was utilized mostly for children and older adults who lived with families in the small towns around the institution. Family care spread quite rapidly to most of the states during the 1930's and was, in essence, the beginning of foster care placement for the retarded.⁵⁷

It is noteworthy that if all of the separate schemes for care of the mentally retarded that were being independently developed in various parts of the country during the first half of this century could have been continued and coordinated, there would have been then established the "continuum of care" concept advocated by the President's Panel of 1962. Instead, this rather progressive trend did not continue to move forward and, in fact, was, by 1955, at a standstill. The new enthusiasm and devoted sense of responsibility for meeting the needs of the retarded had been drained away, and by the mid-twentieth century the impression prevailed that mental retardation was a specialized, isolated area which received little attention or support from society at large.

There have been several theories advanced as to the forces that intruded into the picture to slow down this progressive trend and once again cause services for the retarded to atrophy.

⁵⁷Vaux, C., "Family Care of Mental Defectives," Journal of Psycho-Asthenics, XL, (1934-1935), pp. 101-108.

Wolfensberger (1969) hypothesized that the situation was brought on by the professional workers in the field themselves.⁵⁸ He contends that it was the professionals who had indoctrinated the populace for about 30 years regarding the menace of retardation, and they did little to actively alter this image. Furthermore, although the professional workers may have been applying themselves conscientiously, they remained isolated within the strong walls of the institutions and unconcerned with society's indifference.

On the other hand, Adams (1971) attributes this halt in the extension of community services for the retarded to events of a socio-political nature.⁵⁹ She makes the point that because of the Great Depression, attention was inevitably drawn away from the problems of the relatively small segment of society that the retarded constituted, and focused instead on the survival of the normal working class. The depression plunged almost the entire wage-earning population into economic dependency and, since the successful assimilation of the retarded depends basically upon the existence of a prosperous society, the attempts at rehabilitation and community integration were doomed. Indeed, the records of this period show a reduction of paroles from institutions for the mentally retarded and an increase in admission rates.⁶⁰

⁵⁸Wolfensberger, W., "The Origin and Nature of Our Institutional Models," in Changing Patterns in Residential Services for the Mentally Retarded, A President's Committee on Mental Retardation Monograph, Washington, D. C., 1969, pp. 129-131.

⁵⁹Adams, M., Op. Cit., pp. 44-45.

⁶⁰Matthews, M., "Some Effects of the Depression on Social Work with the Feeble-Minded," Journal of Psycho-Asthenics, XXXIX, (1933-1934).

The second external factor cited by Adams is the advent of World War II. While it did revive the economy, it caused the nation to focus its psychological and material resources on the successful prosecution of the war and thereby greatly, if not totally, obscuring the needs of the mentally retarded.

Both of these positions are certainly valid, and it is probably the combined effects of these; professional indifference to strategies for social change and socio-political factors, that relegated the problems of the retarded to limbo for approximately twenty-five years after 1930..

CHAPTER III

THE IMPACT OF LEGISLATION ON SERVICES TO THE MENTALLY RETARDED

INTRODUCTION

History records that human rights in our society are not guaranteed or protected by good will alone. The fabric of our society, even many of its customs, is dictated, controlled, or modified by law. The American College Dictionary defines a law as "any written or positive rule, or collection of rules, prescribed under the authority of the state or nation..."

As the basic law of our nation, the Constitution of the United States has validity and vitality today largely because it contains statements of principles that are recognized as having wide applicability and credence in today's world. The Fourteenth Amendment, adopted in 1868, stipulates that:

No state shall make or enforce any law which shall abridge the privileges or immunities of citizens of the United States; nor shall any state deprive any person of life, liberty, or property without due process of law, nor deny to any person within its jurisdiction the equal protection of the laws. - Constitution of the United States, Amendment XIV.

The general concept of "equal protection" most readily accepted today is that the law itself must not distinguish arbitrarily between one man and another and that its administration must be equally impartial. Obviously, the twin guarantees of the Fourteenth Amendment, "due process" and "equal protection," do apply, and should apply, to

citizens classified mentally retarded as to others. But history shows that these "guarantees" have brought neither equality before the law nor protection of basic rights to the mentally retarded.

In a working paper prepared for the 1960 White House Conference on Children and Youth, Dr. Gunnar Dybwad called attention to the denial of diagnostic, educational, and other services to mentally retarded persons and commented: "Insufficient attention has been given in the past to the legal status of the mentally retarded child and adult, particularly with reference to the degree of legal protection required as related to the degree of the mental handicap."¹

After a three-year (1967-1970) empirical research study of the mentally retarded and the law, conducted by the Institute of Law, Psychiatry and Criminology of The George Washington University, Dr. Richard C. Allen, Director of the Institute, concluded that:

When the term "rights" was used in relation to the mentally retarded, the reference was usually to the prerogative accorded to relatives and creditors to obtain appointment of a guardian or conservator to prevent waste or destruction of any property that might come into the possession of the retardate; or to the "right" of society to protect itself against the retardate's derelictions and unwanted offspring, by confining and sterilizing him -- generally on no more proof than the fact of his intellectual impairment.²

In more recent years, however, the delivery of services to the mentally handicapped has begun to be viewed as both a "consumer" and a constitutional rights issue. In increasing numbers, handicapped

¹Dybwad, G., Challenges in Mental Retardation, New York: Columbia University Press, 1964, p. 210.

²Allen, R., "Law and the Mentally Retarded," in Menolascino, F. (Ed.), Psychiatric Approaches to Mental Retardation, New York: Basic Books, Inc., 1970, pp. 585-586.

citizens and their advocates, be they parents or professionals, are turning to the courts to secure their rights to treatment, to education, and to a due process hearing -- a right to be heard. Litigation is, in fact, bursting out all over and, at the latest count (April, 1973), there were 35 cases being heard in the courtrooms of 18 states and the District of Columbia.³ Undoubtedly, there will be more to come.

Final solutions to the problems of mental retardation will not lie only with the courts. It is the activities of the Federal and state legislative and administrative branches of government that will ultimately determine society's method of accommodating the mentally handicapped.

Previous evidence notwithstanding, Federal and state legislative programs have had considerable impact upon the fortunes of the retarded. State legislation pertaining to the mentally retarded has tended mainly to follow the thrusts of the Federal Government. It has been noted by Dr. Elizabeth Boggs that the directions of Federal legislation identifiable as being specific to the field of mental retardation has been strongly influenced by two main ongoing phenomena: (1) the continuing and accelerating evolution of public investment, and particularly Federal investment, in delivering health, education, and welfare services to an ever-widening general constituency; (2) the evolution of professional and informed lay opinion, based on experience with the

³Friedman, P., Mental Retardation and the Law: A Report on Status of Current Court Cases, Washington, D. C., U. S. Department of Health, Education, and Welfare, 1973.

mentally retarded in the classroom and the institutions and later in the workshops, clinics, and other community service systems.⁴

In order to fully comprehend the implications of today's fresh demonstration of social concern for the retarded, it is necessary to review the historical development of Federal and state government interest in this segment of our population and the subsequent legislative and programmatic activities that followed.

CHILDREN'S BUREAU - BEGINNINGS OF FEDERAL INTEREST

Established in 1912 by the Federal Government, the Children's Bureau was given the broad mandate to "investigate and report upon all matters pertaining to the welfare of children and child life among all classes of people."⁵ Basically a planning, coordinating, and consultative body, the Bureau's history shows a clear advocacy role for the mentally retarded.

Early after its inception, the Bureau initiated studies on the problems of the mentally retarded in the District of Columbia and, later (1917) in Delaware. The results showed that 82.5 per cent of the retarded lacked appropriate care and stressed the high correlation between mental defect and poverty, abnormal home conditions, neglect,

⁴Boggs, E., "Federal Legislation," in Wortis, J., (Ed.), Mental Retardation: An Annual Review, III, New York: Grune & Stratton, 1971, p. 103.

⁵"History of Children's Bureau activities in behalf of mentally retarded children," in Historical Perspectives on Mental Retardation During the Decade 1954-1964, U. S. Department of Health, Education, and Welfare, Social and Rehabilitation Services, Children's Bureau, No. 426, 1964, pp. 1-3.

and dependency. This was followed up by a study in 1919 of a circumscribed area of Delaware, Sussex County, in which it was again found that most of the mentally retarded were uncared for.⁶

During the years that followed this study, the Children's Bureau acted as a clearing house of information on trends of care for the retarded in the States and thus focused attention on the problem. In 1923, the Bureau undertook a study of work histories of 1,000 former special class pupils from seven different cities. They found that seventy-eight per cent of the boys and eighty per cent of the girls were performing their jobs satisfactorily. While the great majority went into work of an unskilled or semiskilled type, more than half were in manufacturing and mechanical industries. The study, published under the title, Employment of Mentally Deficient Boys and Girls, gave the really first empirical evidence that mentally subnormal persons could function well in industry.⁷

Stimulated by the interest and concern shown by the Children's Bureau, some states began to enact various pieces of legislation to aid the mentally retarded. In 1927, Arizona provided for the creation of a children's colony for the care and education of mental defectives. Kansas enacted a law requiring boards of education to ascertain the number of children in public schools who were three or more years behind in their scholastic achievement, and to provide special classes for them. Minnesota, Indiana, Pennsylvania, and Nebraska all passed

⁶Ibid., p. 3.

⁷Ibid., p. 4.

laws that year relating to the mentally retarded. By 1931, many more states were making efforts to establish programs for the retarded. Connecticut authorized State payments to local school districts providing special classes (\$50 annually per child); Illinois included the mentally retarded in their State Colony for epileptics; Massachusetts was attempting to provide supervision for retarded children outside of school hours; and some states were even dropping the word "feeble-minded" from the names of their state institutions.

The Social Security Act of 1935 also played a part in shaping services for the retarded when the Bureau became the responsible agent for administering Federal Grants for maternal and child health services, crippled children, and child welfare. Following a survey of the medical services available to cope with the problems of retardation, the Bureau established demonstration projects in various states on the medical care required to meet this disability. By 1956, there were twenty-six special demonstration diagnostic and treatment clinics established for mentally retarded children. Presently, there are over 200 such clinics supported by Federal funds.

Throughout its existence, the Bureau provided a corps of consultants to state health departments to work on problems of methods of financing comprehensive care, relationships between state governments, and non-official groups and agencies working in mental retardation, desirable state legislation, and educational programs for professional personnel.⁸ In 1969, the Children's Bureau was absorbed into the newly

⁸Ibid, p. 6.

established Office of Child Development under the Department of Health, Education, and Welfare where it continues to maintain an overall advocacy and leadership responsibility for all children, including children with mental retardation.

These recurring evidences of the Children's Bureau's interest in the mentally retarded are significant in that they represent a major philosophic change in attitude on the part of Federal and, subsequently, state governments. For the first time other alternatives to institutionalization were being considered. State and local public welfare agencies were giving attention to the needs of the mentally retarded child. They were searching for ways of protecting these children from emotional and moral neglect, for methods of providing them with mental stimulation, and giving help to parents in providing more adequate care.

Unfortunately, this early enthusiasm, which was activated by the Government's interest in mental retardation, was soon quenched by overriding concerns of the economic depression of the 1930's and followed by those of World War II. History would have to wait another decade or more until the Kennedy Administration made its unique and powerful impact on public interest, professional opportunity, and official action in relation to mental retardation.

The years of the Great Depression were lean ones indeed for the major public programs in mental retardation, and the impact was felt in state residential care programs and public school special classes. New construction of school buildings came to a standstill just at the time the children born during the post World War I baby boom came of school

age. Under the pressure of rising regular enrollments the "luxury" of special classes for the mentally retarded yielded, and a new definition of "educability" began to be applied to the retarded. Under it, in some states, classes previously established for "imbeciles" were discontinued on the grounds of their pupils' lack of progress in "academic subjects." By 1950 only a handful of local public day school classes for the "trainable" had survived.⁹ Moreover, as mildly retarded youths and their families became the victims of rising unemployment, admissions from this group to state residential institutions began to increase. Between 1920 and 1940, public institutions for the mentally retarded increased from 55 to 90, and the resident population increased from 31,000 to 96,000.¹⁰

These fiscal crises of depression and war, accentuated by the lack of any significant Federal funding, brought about a fifteen-year hiatus in the development of public programs for the mentally retarded.

THE NATIONAL PLAN TO COMBAT MENTAL RETARDATION

The 1950's saw the evolution of a new social phenomenon; the rapid formation of self-organized groups of parents of retarded children. The manner in which their efforts so decisively influenced local, state, and national policy pertaining to the mentally retarded will be fully examined in a later chapter. However, this ground swell of new interest symbolized by the rise of parent groups and the later

⁹Boggs, E., Op. Cit., pp. 104-105.

¹⁰Baumeister and Butterfield, Op. Cit., pp. 18-19.

development of President Kennedy's personal interest in the problems of the mentally retarded, are not totally unrelated.

During the late 1950's it was known, but seldom mentioned, that former Ambassador Joseph P. Kennedy had a retarded daughter. It was no secret that the family, through the Joseph P. Kennedy, Jr. Foundation, made significant contributions to assist facilities for the care, training, and treatment of the retarded primarily under Catholic auspices. But the personal reasons for the family's interest was not publicized and their apparent wishes for privacy were respected.¹¹

However, after his election as President, John F. Kennedy began to show an almost immediate interest in the problems of the mentally retarded. Shortly after the publication of the 1960 White House Conference on Children and Youth Report, President Kennedy decided to appoint an ad hoc study group to consider the nation's responsibilities in research, training, and service related to the prevention and management of mental retardation. In October, 1961, he established a twenty-seven-member President's Panel on Mental Retardation. The opening paragraph of his charge to the members spoke to the timeliness of the Panel's mission:

The manner in which our Nation cares for its citizens and conserves its manpower resources is more than an index to its concern for the less fortunate. It is a key to its future. Both wisdom and humanity dictate a deep interest in the physically handicapped, the mentally ill, and the mentally retarded. Yet, although we have made considerable progress in the treatment of physical handicaps, although we have attacked on a broad front the problems of mental illness,

¹¹ Shriver, E. K., "Hope for the Retarded," Saturday Evening Post, September, 1962, pp. 71-75.

although we have made great strides in the battle against disease, we as a nation have far too long postponed an intensive search for solutions to the problems of the mentally retarded. That failure should be corrected.¹²

The members of the Panel, under the leadership of Leonard W. Mayo, were organized into six task forces. After holding a series of public hearings throughout the country and listening to the testimony of professional workers, parents, and interested community leaders, they prepared a final report containing some ninety-seven recommendations.

On October 16, 1962, the President's Panel on Mental Retardation submitted its official report to President Kennedy. It contained some depressing accounts of the status of the retarded. For example, it noted that there were only 500 full-time doctors to care for 160,000 residents in institutions; that the national average cost per day per resident was \$4.55; and that any objective study of the rights of the mentally retarded under the law had been grossly neglected.¹³ The report stressed the need for greatly increased Federal expenditures for expanded research, better educational and training facilities, more prenatal care, increased rehabilitation services, and improved public attitudes toward the retarded.

¹²Kennedy, J. F., "A Statement by the President Regarding the Need for a National Plan in Mental Retardation," in A National Plan to Combat Mental Retardation, Washington, D. C., U. S. Government Printing Office, 1962, p. 196.

¹³"A Proposed Program of National Action to Combat Mental Retardation," The President's Panel on Mental Retardation, Washington, D. C., U. S. Government Printing Office, 1962, pp. 3-7, 150.

Some of the specific recommendations concerning the organization, planning, and coordination of services included:

1. The Secretary of Health, Education, and Welfare should be authorized to make grants to States for comprehensive planning in mental retardation.
2. The Governor of each State and his staff should review the array of major services outlined in the report, identify the branch of State government which is, or should be, discharging each responsibility noted; and assess the extent to which each function should be strengthened.
3. Each State should make arrangements through such means as an interdepartmental committee, council or board, for the joint planning and coordination of State services for the mentally retarded.
4. Within each State department with a major concern for mental retardation, there should be a division or bureau to administer services to the mentally retarded or a special consultant with department-wide responsibility for the development and coordination of these services.
5. The Department of Health, Education, and Welfare should give special attention to the use of professional and citizen advisory groups in relation to its program on mental retardation.
6. The Department of Health, Education, and Welfare should consistently reinforce the principle and practice of comprehensive planning and coordination at the regional, state, and local levels.¹⁴

It was within the framework of this new and strong national concern with mental retardation that Federal legislation was designed and ultimately passed by Congress.

The first bill implementing the Kennedy program to combat mental retardation, "The Maternal and Child Health and Mental Retardation Planning Amendments Act of 1963," (Public Law 88-156) came into

¹⁴Ibid., pp. 164-167, 186.

being in October, 1963. The bill authorized funds for grants to the States to begin comprehensive mental retardation planning on a coordinated interagency basis and amended the Social Security Act:

...with the objective of assisting States and communities, in preventing and combating mental retardation through expansion and improvement of the maternal and child health and crippled children's programs, through provision of prenatal, maternity, and infant care for individuals with conditions associated with childbearing which may lead to mental retardation, and for other purposes.¹⁵

This legislation was characterized by two important features that were destined to have major and continuing impact to the present day. First, the emphasis placed on preventive measures through an extension of health services to mothers and infant care in high-risk areas, carried with it the admission that the cycle of poverty and mental retardation were closely connected. Second, the provision of means for stimulating services at a local level, but on a nationwide scale, through Federal grants, gave mental retardation a national context. It implied that such a prevalent and seriously handicapping condition could not be properly dealt with by local resources alone but needed Federal backing.¹⁶

Furthermore, there were significant philosophical implications of this Act which, while greatly commendable and desirable, are still far from being accepted by our society today. Specifically, the Act provides for care to the most disabled and least socially productive

¹⁵U. S. Department of Health, Education, and Welfare, A Summary of Selected Legislation Relating to the Handicapped 1963-1967, Washington, D. C., U. S. Government Printing Office, 1968, pp. 1-2.

¹⁶Boggs, E., Op. Cit., pp. 118-119.

members of the nation. As such, it fosters the concept of social welfare for all - namely, that the deficiencies of the weak and less well endowed should be the responsibility of the total society in which they live and subsidized by the total society.

The second important piece of legislation to evolve from the recommendations of the President's Panel on Mental Retardation was the "Construction of Research Centers and Facilities for the Mentally Retarded Act" (P.L. 88-164). It was signed by the President in October, 1963 and pertained to Federal grants for the construction of facilities for the "diagnosis, treatment, training and custodial care" of the mentally retarded (including "clinical" facilities affiliated with universities for the purpose of training personnel) and for the construction of comprehensive research centers in mental retardation.¹⁷ This legislation indicated a thrust for services in the direction of training professionals in the field at all levels of preparation - from teacher training to the training of college instructors, research personnel, and the administrators and supervisors of teachers of the handicapped.

The 1965 Amendments to this Act (P.L. 89-105) authorized a \$224 million program of grants for staffing community mental health centers and, in addition, extended and expanded the existing grant program for training teachers of handicapped children and for research and demonstrations in the education of handicapped children.

¹⁷A Summary of Selected Legislation Relating to the Handicapped 1963-1967, Op. Cit., pp. 2-3.

Motivated by the numerous recommendations of the 1963 National Plan to Combat Mental Retardation, the legislative developments from 1963 onward were of considerable significance in furthering the cause of the retarded.

The Vocational Rehabilitation Amendments of 1965 (P.L. 89-333) broadened the variety of modalities for the improvement and expansion of sheltered workshops. Technical consultation, construction funds, training stipends, and initial staffing funds were some of the instruments added.¹⁸

The Elementary and Secondary Education Act of 1965 (P.L. 89-10) made it clear that handicapped children, including the mentally retarded, were to be considered "educationally disadvantaged." It helped school districts to provide educational summer camps for mentally retarded children, to expand or improve special programs, and to strengthen the leadership resources of State education departments.¹⁹

The 1965 Social Security Amendments (P.L. 89-97) increased the benefits payable to Social Security beneficiaries, including the adult disabled children of formerly covered persons. It laid the groundwork for medical assistance to be paid to, or on behalf of, needy persons requiring skilled nursing care in State and private institutions for the retarded, and permitted Social Security trust funds to be used for the rehabilitation of beneficiaries.²⁰

¹⁸Ibid., pp. 4-5.

¹⁹Ibid., pp. 11-12.

²⁰Ibid., pp. 13-14.

An inconspicuous provision in the 1965 amendments of the Immigration Act, for the first time, enabled retarded would-be immigrant children to accompany or join their close relatives in this country under certain stringent conditions.²¹

The overall effect of the findings of the first President's Panel on Mental Retardation was to enhance the passage of an impressive array of legislation to deal with the far-reaching and complex problems of mental retardation on a national scale. It represented an explicit acknowledgment by the "Great Society"²² that individuals and families who came under the shadow of this handicap needed and merited nationwide and permanent assistance. Like the peak development of previous eras, this somewhat rapid and dramatic expansion of care for the mentally retarded was related to certain dominant educational-social-political features of the times. Namely, the humane values engendered by the Kennedy Administration and the advanced state of knowledge in the medical and social sciences.

PRESIDENT'S COMMITTEE ON MENTAL RETARDATION

The span of years from 1966 to 1971 was marked by spectacular changes in the outlook of both the macrocosmic American society and microcosm that is the world of the mentally retarded. Basically, it was not a propitious time for new Federal initiatives in the field of mental retardation.

²¹Boggs, E., Op. Cit., p. 125.

²²Ibid., p. 124.

During the Kennedy Administration, legislation pertaining to mental retardation had, in general, enjoyed bipartisan support in the Congress. Therefore, in 1966, active professional and lay constituency were understandably optimistic about President Johnson's willingness to carry these new programs forward. All these hopes were dashed; however, when the President's long awaited message on health to the Congress failed to contain any proposals concerning the needs of the mentally retarded.²³ Neither was there any consideration given to those parts of the current legislation that required extensions for authorization or funding.

Instead, the President created, by executive order, a President's Committee on Mental Retardation (PCMR) as an ongoing advisory body under one chairmanship of the Secretary of the Department of Health, Education, and Welfare.²⁴

The significance of this action is that, for the first time, there was opportunity for great influence to be exerted, on behalf of the mentally retarded, from within the government itself. It is important, therefore, to determine the effectiveness of PCMR in this advocate role.

The committee (PCMR), with its rotating membership, has continued throughout the Johnson and Nixon Administrations. The first

²³Boggs, E., "Federal Legislation," in Wortis, J., (Ed.), Mental Retardation: An Annual Review, IV, New York: Grune & Stratton, 1972, p. 165.

²⁴Brewster, D., "Domestic Health," Congressional Record, March 25, 1966, p. 6467.

annual report, MR 67, was devoted primarily to documenting progress since the President's Panel in 1962. Little, if any, direct impact can be noted.²⁵

MR 68, issued by PCMR during Wilbur Cohen's tenure as Secretary of HEW, highlighted three "priority reports" on residential care, manpower, and mental retardation in poverty areas. It recommended "greatly increasing funds" in improving state institutions and "greatly expanded" Federal support of grants and scholarship awards to develop manpower needs in the field of mental retardation.²⁶

The third annual report of PCMR, MR 69 - Toward Progress: The Story of a Decade, mainly served as a review vehicle for the new incoming Administration. Other than calling attention to the facts of poverty-retardation relationships, it made no significant recommendations.²⁷

By midsummer of 1970, the complexion of the Committee began to change. Partisan loyalty became a more critical factor in nomination. The balance in PCMR began to shift from professional to citizen leadership. Medicine began to give way to law as the profession most prevalent.²⁸ This shift to the law profession apparently gave the

²⁵President's Committee on Mental Retardation; MR 67 - A First Report, Washington, D. C., U. S. Government Printing Office, 1967.

²⁶_____, MR 68 - The Edge of Change, Washington, D. C., U. S. Government Printing Office, 1969.

²⁷_____, MR 69 - Toward Progress: The Story of a Decade, Washington, D. C., U. S. Government Printing Office, 1969.

²⁸Boggs, E., Op. Cit., p. 167.

Committee the resources to move into an area yet untouched; in MR 70, the Committee addressed itself to inquiry regarding the "constitutional rights and guarantees of the mentally retarded."²⁹ It is noteworthy that approximately three years later, in May, 1973, PCMR held the first national conference on "The Mentally Retarded Citizen and the Law."³⁰

In its fifth annual report, MR 71, the Committee under the chairmanship of Elliot L. Richardson, the Secretary of HEW, focused its attention on the "societal conditions in which retardation is bred and thrives." It suggested that strong efforts be made to mobilize coordination between Federal agencies and recommended the use of existing legislation and the courts, if necessary, to achieve educational justice for mentally retarded children.³¹

Finally, in its MR 72 recommendations, made now under the chairmanship of the current Secretary of HEW, Caspar W. Weinberger, the Committee reaffirmed the two national goals set forth by President Nixon:

1. To reduce by half the occurrence of mental retardation in the United States before the end of this century.

²⁹President's Committee on Mental Retardation; MR 70: The Decisive Decade, Washington, D. C., U. S. Government Printing Office, 1970.

³⁰_____, PCMR Message, Washington, D. C., U. S. Government Printing Office, June, 1973.

³¹_____, MR 71: Entering the Era of Human Ecology, Washington, D. C., U. S. Government Printing Office, 1971.

2. To enable one-third of the more than 200,000 retarded persons in public institutions to return to useful lives in the community.³²

In addition to describing some model programs in various parts of the nation, the Committee again called for coordination between governmental agencies and for the focusing of resources to create greater public awareness.

The cumulative evidence of the past six years suggests that the efforts of PCMR had little direct impact on Federal legislation and increased funding. Nevertheless, it was able to move in a timely way to focus attention on the issues of poverty and mental retardation, better coordination of Federal activities, legal and educational rights of the retarded, and State, regional, and local responsibility in planning, funding, and provision of services.³³ Rather, it was the combined efforts of the professional workers in the field and voluntary organizations such as the National Association for Retarded Children that aided in the passage of legislation benefiting the retarded during the span of years from 1966 to 1972.

Most noteworthy was the passage of the Developmental Disabilities Services and Facilities Construction Amendments of 1970 (P.L. 91-517). This new legislation is designed to provide states

³²President's Committee on Mental Retardation; MR 72: Islands of Excellence, Washington, D. C., U. S. Government Printing Office, 1972.

³³Boggs, E., Op. Cit., pp. 168-169.

with broad responsibility for planning and implementing a comprehensive program of services and to offer local communities a strong voice in determining needs, establishing priorities, and developing a system for delivering services.

Furthermore, program offerings are broadened to include not only the mentally retarded but also persons suffering from other "serious developmental disabilities originating in childhood."³⁴ Presently, mental retardation, cerebral palsy, and epilepsy are the only handicapping conditions being considered as eligible for service.

For FY 1973 an appropriation of \$170,000,000 was authorized for Federal (70%) matching grants to States. In effect, this most recent piece of legislation gives much more discretion to the States and allows for a wider categorization of beneficiaries.

PARTICIPATION BY THE STATE GOVERNMENTS

As has been noted, President Kennedy's historic proposals to the 88th Congress called for action on many fronts in the mental retardation field. A pattern of vastly increased Federal concern for the retarded, accompanied by substantial increases in appropriations, had begun. State governments were encouraged through Federal grants to become directly involved in planning comprehensive actions to combat mental retardation.

³⁴U. S. Department of Health, Education, and Welfare, A Summary of Selected Legislation Relating to the Handicapped, 1971, Washington, D. C., U. S. Government Printing Office, 1971, pp. 1-2.

Of the 55 eligible jurisdictions, 54 participated and, in 1965, the resulting activity culminated in a massive coordinated and comprehensive planning effort by each State and territory in the nation. All States were requested to develop a coordinated policy approach to programs for the retarded within their jurisdiction, and to provide an opportunity for all concerned citizens, experts, and officials to contribute their knowledge and opinions.³⁵

TEXAS PLAN TO COMBAT MENTAL RETARDATION

The Texas mental retardation planning project, like those of the other States, had its inception in legislation proposed by President Kennedy and signed less than a month before his assassination.

Texas was one of the first States to receive a basic planning grant. To implement this program, Governor John Connally, in July, 1964, appointed an eight-member Inter-Agency Committee composed of the commissioners of the principal State agencies with programs or responsibilities for the mentally retarded. The Governor also appointed a 53-member Advisory Committee of citizens, specialists, and lay people interested in the total scopes and problems of mental retardation. (The writer served on the Committee as chairman of the Vocational Rehabilitation Task Force.)

Public briefings were held in 17 major cities. Thousands of Texans, from all walks of life, came to hear a detailed overview of

³⁵President's Panel on Mental Retardation, 1962, Op. Cit., pp. 165-166.

the problems involved in mental retardation and of its scope. Immediately after the public briefings were held, Governor Connally requested the mayors of sixty key cities in the State to appoint a Commission on Mental Retardation Planning. The purposes of the commissions were two-fold: to obtain detailed information concerning existing local facilities, services, and needs and to evaluate this information in terms of coordination and long-range planning for service program needs within the local study area. Each locality viewed their needs in terms of programs related to health, rehabilitation, education, welfare, day care, residential care, recreation, public awareness, and the law. Task forces for each category were formed.

The completed reports of the local task force groups were forwarded to the State Planning Office by April, 1965. The information collected by the sixty commissions was analyzed through the use of high speed computers, and the results given to the State-level Task Forces for further study and coordination.

Each of the twelve State-level Task Forces formulated a single plan for coordinated State and local action to meet the needs of the mentally retarded. These were blended into a single workable plan, and after numerous debates, hearings, and rewritings, a final draft of the Texas Plan to Combat Mental Retardation was approved by the State Advisory Committee and presented to the Governor in March, 1966.

The Texas Plan contained no less than 200 separate recommendations which were directed to the attention of the Governor, the Legislature, State Government agencies with responsibilities serving retarded citizens, public officials at city, county, and regional

levels, and local citizen groups.³⁶ The recommendations were based upon the findings of the local task forces which indicated that Texas was definitely not, at that time, a leadership state in providing services to the mentally retarded.

For example, in 1966, Texas law made no provision for the guardianship of mentally retarded persons, nor for affording them their civil rights. There were six State Schools in Texas with a combined bed capacity of 11,500. Day care services were practically nonexistent. Out of 254 counties in Texas, 88 reported no educational services for the mentally retarded.³⁷

The main theme of the multitude of these recommendations addressed itself to the development of community services and retention of the mentally retarded in the home community. The assumptions made throughout the Texas Plan to Combat Mental Retardation were that:

1. Local services are more effective and desirable in most instances than State institutional services;
2. Avoiding or alleviating the problems of retardation will pay, rather than cost, in the long run;
3. Most retarded persons can become assets rather than liabilities to their communities.³⁸

In 1965, the 59th Texas Legislature, with the urging of the members of the State Advisory Committee, enacted the "Mental Health

³⁶Governor's Advisory Committee on Mental Retardation Planning, Recommendations For The Development of the Texas Plan to Combat Mental Retardation, Austin, Texas, March, 1966, pp. 7-15.

³⁷Ibid., pp. 15, 21, 27.

³⁸Ibid., p. 28.

and Mental Retardation Act," (H. B. 3). Although the Act was passed several months prior to the formal completion of the Texas Plan to Combat Mental Retardation, its conception was derived from the findings and subsequent recommendations of the Committee. The Act created a new department in the State governmental structure, the Texas Department of Mental Health and Mental Retardation (TDMHMR), whose stated purpose regarding the mentally retarded was:

...to provide, coordinate, develop, and improve services to the mentally retarded of this State to the end that they will be afforded the opportunity to develop their respective mental capacities to the fullest practical extent and to live as useful and productive lives as possible.

In addition, the legislature declared through this Act that the public policy of the State would be:

...to encourage local agencies and private organizations to assume responsibility for the effective administration of mental health and mental retardation services, with the assistance, cooperation, and support of the Texas Department of Mental Health and Mental Retardation.³⁹

The Board for Texas State Hospitals and Special Schools was replaced by TDMHMR, and all of the State hospitals and State schools came under the jurisdiction of the new department. Further, Articles 3 and 4 of the Act mandated that TDMHMR support the establishment and operation of community service centers at the local county level and to supply "State Grant-in-Aid" funds to provide adequate services to meet the needs of the mentally retarded at the local community level.⁴⁰

³⁹Texas Legislature, Mental Health and Mental Retardation Act, House Bill 3, the 59th Legislature, Regular Session, p. 165, Ch. 67, effective September 1, 1965, State of Texas, Austin, Texas, 1965.

⁴⁰Ibid., pp. 10-13.

Clearly, this momentous piece of legislation and the accompanying Texas Plan to Combat Mental Retardation set forth the battle plan for a massive assault against the ravages of mental retardation in the State of Texas. The battles were to be fought in the communities of Texas and not in its institutions. The weapons were to be forged through increased services and not more institutions.

However idealistic they may be, plans that do not result in action are simply philosophic exercises; and enlightened legislation is only effective upon its implementation. Now, in 1973, after seven years of "action" and "implementation," how much has been accomplished in Texas so as to make its communities more inhabitable for its mentally handicapped citizens?

In FY 1972, the total operating cost for TDMHMR was \$115,247,000. Six per cent of this amount (\$7,229,000) was spent for community services to the retarded while forty-four per cent (\$50,267,000) was spent for State institutions for the retarded.⁴¹ In 1966, there were six State institutions for the mentally retarded. In 1972, there were eleven State institutions, and two more scheduled for construction. The total resident population in those six State institutions in 1966 was 10,241, and in 1972, there were 13,267 residents living at the eleven institutions.⁴² As late as 1971, there

⁴¹Texas Department of Mental Health and Mental Retardation, Annual Report, 1972, Austin, Texas, 1972, p. 40.

⁴²Ibid., p. 15.

were 2,447 persons in the State institutions who had I.Q.'s above 55 and who were more than fifteen years of age.⁴³

On the brighter side, in 1966, there were no State-sponsored community centers for the mentally retarded, whereas, by 1972 twenty-four such centers had been established throughout the State of Texas.

While the evidence to date, indicates a curious ambivalence on the part of State and Federal government officials as to the direction programs for the retarded should take, there is no doubt as to the intent of the law and the mandate of the public. Attitudes, expectations, even values are in a state of rapid change throughout the United States today. What was long taken for granted is now questioned and challenged. The "accepted ways," (i.e., unquestioned institutionalization) of dealing with social problems are no longer accepted. People are asserting their rights - as women, as students, as members of ethnic minorities. Those who cannot speak for themselves, such as the mentally retarded, have attracted spokesmen: an evergrowing body of qualified professionals, a larger number of influential community citizens, young people, and parents of the handicapped (more sophisticated now in bespeaking the interests of their retarded sons and daughters).

Although the charismatic bloom, given to the cause of mental retardation during the early Kennedy years, is gone, the gains of the

⁴³Texas Rehabilitation Commission, Comprehensive Statewide Plan for the State Schools, Austin, Texas, 1973, p. 8.

past decade are now part of the system. While the rate of advance may be slow, there are now more permanent mechanisms for coping with the social challenge of retardation. Federal funding continues; the State comprehensive plans to combat mental retardation are a matter of record; litigation activity in the courts has begun; and sufficient community mechanisms now exist for improving and establishing services.

CHAPTER IV

DEVELOPMENT OF THE PARENT GROUP MOVEMENT

INTRODUCTION

In a society as complex as the United States, many individuals with grievances have felt themselves incapable of exerting sufficient influence on the political system to correct these grievances.

To some extent other groups, professional or administrative (i.e., The American Association on Mental Deficiency; The Council for Exceptional Children) have established themselves as champions of these persons with grievances. They have provided what Holtzman labels "virtual representation."¹ Virtual representation has been particularly common in areas of social need, such as health, education, and welfare, where government experts and professionals alike have professed to know more than those in need what they needed.

However, in the period following the Second World War, groups of formerly inactive individuals with common grievances moved from "having grievance without engaging in political action to action as political interest groups."² It has been conceptualized by Truman that

¹Holtzman, A., Interest Groups and Lobbying, New York: Macmillan Co., 1966, pp. 7-8.

²Lerner, H., State Association for Retarded Children and New York State Government, 1948-1968, New York: New York Association for Retarded Children, Inc., 1972, p. 329.

these unorganized interests had always held within them the possibility of future development from potential to actual political interest groups.³

In studying the unusual dynamism of "self-organized groups" for the handicapped, Katz sets forth the hypothesis that the common origins of the parent groups lie in the need felt by parents of children with a similar handicap to receive greater assistance in the diagnosis, treatment, and care of their children than had hitherto been available from professional and community sources. In banding together for action on their problems, the parents achieve a sense of shared purpose and enthusiasm which stimulates them to an intense degree of volunteer activity.⁴

HISTORICAL DEVELOPMENT

The formation of self-organized groups of parents of retarded children has been a relatively recent occurrence in the development of social welfare organizations in this country. This self-help movement began in the early 1930's as a spontaneous reaching out of parents to one another, eager to share their similar problems and concerns.

It has been speculated that, while no visible power moved these scattered bands of relentless parents to seeking solutions to

³Truman, D., The Governmental Process, New York: Alfred Knopf, 1958, pp. 114-115.

⁴Katz, A., Parents of the Handicapped, Springfield, Ill.: Charles C. Thomas, 1961, pp. 122-123.

their distress, an inner force drove them along new pathways.⁵ However, Lerner makes the point that the freer emotional environment prevailing after World War II led to a reduction of personal guilt and shame which might have impeded earlier attempts at organization of parent groups for the retarded.⁶ On the other hand, the literature indicates a strong development of parent activity in the early 1930's and 1940's which was based primarily on the solution of individual problems.⁷ As an example of these early efforts, in 1933, five mothers in Cuyahoga County, Ohio, met to express their indignation because their mentally retarded children had been excluded from public school classes. From this meeting, the Council for the Retarded was organized and it was successful in obtaining a special class to meet the needs of those retarded children who could not adapt to the regular school program.⁸

Other groups of parents of retarded children in different parts of the country began to meet together. In New York, Boston Washington, and New Jersey small groups were formalizing into chartered organizations. The focus of these early organizations was primarily related to obtaining services to meet the needs of the members' children in their own local community. This gathering together of parents with similar problems enabled them to discuss openly their

⁵Boyd, D., The Three Stages, New York: National Association for Retarded Children, 1959, p. 1.

⁶Lerner, H., Op. Cit., p. 330.

⁷Weingold, J., Parents Counseling Other Parents of Retarded Children, New York: New York State Welfare Conference, 1960, p. 4.

⁸Segal, R., Mental Retardation and Social Action, Springfield, Ill., Charles C. Thomas, 1970, p. 23.

anxieties, fears, and guilt and helped them move toward a more enlightened view of the causes and nature of mental retardation.

It was not until 1946 that some indication began to develop that these parent groups might be interested in expanding their concerns and efforts to encompass the needs of all retarded children, wherever they may be. A paper was presented at the annual meeting of the American Association on Mental Deficiency which focused attention on this newly emerging phenomenon.⁹ Evidence was presented which indicated a prevailing commonality of problems and concerns. All institutions for the mentally retarded needed to be improved. All public school systems evidenced limitations in the provision of adequate programs for retarded children. There was a uniform need to educate the public about mental retardation and to eradicate the hopeless concept that nothing could be done. There were practically no community programs available to the retarded anywhere.

By 1949 a number of state associations had been established to coordinate the work of local groups. Leaders began to recognize that more could be accomplished in unification of the scattered state and local units. It was at the May, 1950 annual meeting of the American Association on Mental Deficiency that Joseph T. Weingold, parent of a retarded child and executive director of the New York City Association for the Help of Retarded Children proclaimed, "This sense of inevitability must not be dissipated in local action only. This and now is the

⁹Sampson, A., "Developing and Maintaining Good Relations with Parents of Mentally Deficient Children," American Journal of Mental Deficiency, XII, No. 2, October, 1947.

time for all parents' groups to join together into a national organization or federation. Our problem is nationwide."¹⁰ A meeting was scheduled in Minneapolis for September, 1950, to which representatives from parents' groups throughout the country were invited to discuss the proposed establishment of a national organization. It was there that the National Association for Retarded Children (NARC) breathed for the first time.¹¹

Today, the National Association for Retarded Children is represented in all fifty states by more than 1,500 state and local units. Its membership consists of more than 180,000 members. The organization of NARC is based upon a loose federated structure of state and local associations. Each of these state and local units operates on an autonomous basis. While the National Association develops standards and policies, the local and state associations interpret these policies according to their own needs. Yet, despite the looseness of the structure, there does appear to be a force that binds the group together. Its "grass roots" identity seems to come from the strength of its local units, and perhaps this may account for its credibility as a force for social change.

¹⁰Weingold, J., "The Formation of Parents' Groups and the Relation to the Overall Problem of Mental Retardation," a paper presented at the Annual Meeting of the American Association on Mental Deficiency, Columbus, Ohio, May 17, 1950.

¹¹Segal, R., Op. Cit., p. 26.

IMPACT ON LEGISLATION

Social action processes are very complex. Information about what actually takes place in the interaction between various "actors" or groups involved in effecting social change is often of such an informal nature that it is, in many instances, non-specific.

Although the principle objectives of NARC encumber all aspects of the general welfare of all mentally retarded persons, its major influence was felt in the arena of national legislation benefiting the retarded. Its mission was twofold: to determine what, in fact, was being done within and by Federal agencies and to stimulate those having implicit responsibilities to pursue and discharge them more explicitly. The March, 1955 issue of Children Limited, the NARC newspaper, announced under a Washington dateline of March 18, that "History was made for retarded children on a national scale today when the House Appropriations Committee urged an all out attack on the 'great growing problem.'" In addition to earmarking \$750,000 to launch new research in mental retardation, the Committee also made it clear that it expected the Office of Education to present a "real program" when it came before the Committee in 1956.¹² It was not long before the professional staff members of the relevant Federal agencies began to respond.

¹²Boggs, E., "Federal Legislation," in Wortis, J. (Ed.), Mental Retardation: An Annual Review, III, New York: Grune & Stratton, 1971, p. 109.

Although non-partisan in nature, NARC actively sought the aid of elected representatives to their cause. One such was the late Congressman John E. Fogarty of Rhode Island who initiated substantive legislation on behalf of the retarded. Early in 1956, NARC presented Congressman Fogarty with a detailed comprehensive statement calling for intensified action not only in the Office of Education but also in the Children's Bureau, Office of Vocational Rehabilitation, and the Bureau of Public Assistance.¹³

The record indicates that, from 1955 to 1967, NARC exercised significant influence in the passage of appropriation bills which earmarked money for mental retardation research, cooperative research in education, diagnostic facilities, and day care services. In addition, the Association, through its intervention and support, assisted in obtaining changes in governmental policies, such as changes in the interpretation of the Hill-Burton Act to eliminate the automatic exclusion of funding for mental retardation institutions, changes in regulations in the Fair Labor Standards Act regarding sheltered workshops, changes in the interpretations of governmental admissions of mongoloids as permanent immigrants, and changes in regulations regarding protective payments under the program for Aid to the Permanently and Totally Disabled.¹⁴

More recently, NARC played a prominent role in the passage of the Developmental Disabilities Services and Facilities Construction Act

¹³Ibid., p. 111.

¹⁴Segal, R., Op. Cit., pp. 30-31.

of 1970 (P.L. 91-517), the Wagner-O'Day Amendments of 1971 (P.L. 92-28) which extended special preference in bidding on government contracts to workshops for the severely handicapped, and the Economic Opportunity Amendments of 1972 (P.L. 92-424) which requires that not less than ten per cent of Headstart enrollments be made available to handicapped children.¹⁵

IMPACT ON PUBLIC ATTITUDE

From the beginning of its existence in 1950, the National Association for Retarded Children has emphasized public awareness and the need for public acceptance. One of its principle objectives stated in its bylaws is: "To develop a better understanding of the problems of mental retardation by the public."¹⁶ Undoubtedly, this same objective is prominently included in the bylaws of each of the 1,500 state and local associations affiliated with NARC.

Programs of public awareness and public education and information have been a major and traditional function of every parent organization practically from the moment of formal establishment. Some of the most important achievements in NARC's history were the early articles in national magazines, the spot announcements on radio and later television, the syndicated feature articles in the daily press,

¹⁵Gettings, R., 92nd Congress: Federal Legislation Affecting the Mentally Retarded & Other Handicapped Persons, Arlington, Va., National Association of Coordinators of State Programs for the Mentally Retarded, Inc., 1973, pp. 16-17.

¹⁶National Association for Retarded Children, Policies and Constitution and Bylaws, New York. Revised, January, 1966.

the public acknowledgments by prominent persons that they had retarded children. Indeed, these were substantial accomplishments for an organization which sought to focus on one of the most sensitive and misunderstood subjects in human society.

Yet in more than twenty-five years, although public awareness has certainly increased and there is spotty evidence of public acceptance (in the sense of toleration, at least), there has not been the meaningful change in attitudes which is necessary for development of appropriate and adequate programs of service and full inclusion of the retarded in our society.

In his investigation of attitudes toward the handicapped, Lippman makes the charge that, in contrast to Europeans, the "attitudinal set" of Americans toward the handicapped, and the mentally retarded in particular, is basically "rejective" and "lacking in human interdependency."¹⁷

Bernard Posner, Deputy Executive Secretary of the President's Committee on Employment of the Handicapped, cites the results of attitude studies made in the United States between the period 1970-1972.

Roper Research Associates sampled the attitudes of 1,500 American households -- the same sampling used in predicting Presidential elections. It found:

More than half of the people felt that institutionalization was best for the mentally retarded.

Only 16 per cent felt that the retarded should be permitted to work side-by-side with others.

¹⁷Lippman, L., Attitudes Toward the Handicapped, Springfield, Ill., Charles C. Thomas, 1972, p. 5.

The State of Minnesota, in a sample survey of 900 families on attitudes toward the retarded, found that more than fifty per cent felt the retarded to be "useless" and "inferior" when compared with the non-retarded.¹⁸

In a review of recent literature on attitudes toward mental retardation (1973), Harth concludes that "people hold rather strong and divergent attitudes about mental retardation,..." while exhibiting a "general lack of knowledge and interest in mental retardation."¹⁹

Sociologist Thomas P. Holland (1971), in his analysis of current policies and practices in the field of mental retardation, finds that "large-scale changes in public acceptance and valuation of the retarded or in the place of the retarded in society still seem slow in coming."²⁰

Obviously, the massive effort of NARC since 1950, and its 1,500 parent affiliate organizations, to make the public aware of mental retardation and to establish a more receptive and accepting atmosphere for retarded persons has had minimal impact since public opinion studies indicate basic understanding and acceptance do not go deep in the American attitudinal structure. Several viewpoints have been advanced to explain this unique circumstance.

¹⁸Posner, B., "Changing Attitudes Toward Retarded People," in Programs for the Handicapped, Office of Mental Retardation Coordination, Washington, D. C., U. S. Department of Health, Education, and Welfare, Dec. 15, 1972, pp. 4-10.

¹⁹Harth, R., "Attitudes and Mental Retardation: Review of the Literature," The Training School Bulletin, February, 1973, Vol. 69, No. 4, pp. 150-163.

²⁰Holland, T., "Changing Social Policies on Mental Retardation," Journal of Social Issues, Vol. 27, No. 3, 1971, pp. 251-257.

Historically, the major accomplishments of local parent groups have been directly related to the needs as determined by the immediate membership. Segal's study of the membership composition of parent associations for the retarded indicates that the majority of the members came from white, middle-class families; and there were few members from the economically deprived and culturally disadvantaged group.²¹ Yet the largest number of the mentally retarded come from this socioeconomic group.

The causal relationship between such national problems as poverty and inadequate medical care and mental retardation points to the need for a different strategy in seeking to improve the lot of the retarded. Holland suggests that the definition of goals could be more modified from only seeking more services for the mentally retarded to the more positive terms of services to promote the healthy development of all children.²² Such a policy, he contends, would allow for a greatly broadened base of popular involvement and political support for the movement. In effect, a nation that is permitted to be complacent about the problems of poverty, housing, and employment will tend to be equally as insensitive to the needs of the mentally retarded.

Lippman contends that the programs and prospects for mentally retarded persons in European countries are much better than in the United States because a different set of attitudes and values prevails.

²¹Segal, R., Op. Cit., p. 153.

²²Holland, T., Op. Cit., p. 260.

In his interviews with European public officials, citizen-parent leaders, journalists, and professional people working with retarded children and adults, he found they all expressed attitudes and expectations which are markedly different from the prevailing views of their American counterparts. There were three basic attitudes that were expressed most frequently:

1. Mentally retarded people are human beings. They should, therefore, be treated with respect for their individual dignity.
2. We do not always know what capacities a retarded person may have, but we must do all we can to help each one achieve his fullest potential.
3. It is society's responsibility to help the retarded, as it must help others who are handicapped or dependent.²³

It is from these attitudes, says Lippman, that a whole series of programs and policies flows and makes them outstanding. While in contrast, we find in America a sentimental and continual "infantilization" of the mentally retarded coupled with inadequate public appropriations, wretched staff-resident ratios in institutions, and a complacent acceptance of discrimination and mistreatment which we have the power to change but choose to allow.

IMPACT ON COMMUNITY PROGRAMS

During the 1950's, the formation of self-organized parent groups for the mentally retarded followed a similar pattern throughout

²³Lippman, L., Op. Cit., pp. 6-7.

the United States. Usually it was brought into being as a direct result of an advertisement placed in a local newspaper by one or more parents of retarded children who were interested in having others join them in a specific project pertaining to the needs of their particular child or children.

The atmosphere at these first early public meetings has been described as many times having some of the character of a revival meeting, with parents rising emotionally to discuss their own experiences and problems.²⁴ Nevertheless, those who attended seemed to have little doubt of the appropriateness of forming a specific organization devoted to the interests of mentally retarded children. At these initial public meetings, a committee was usually appointed immediately to formulate a constitution and statement of aims for the new organization. Subsequent meetings dealt with ratification of constitutions and bylaws, election of officers, appointment of members to different committees, and, finally, the establishment of a specific program of service. In most instances, the first service programs to be implemented emanated from the needs of the children of the most active members. Usually, these were services not available anywhere in the community. Depending upon the state of development of a particular community, these service programs ranged from a class for preschool retarded children to a work activity center for retarded adults.

²⁴Katz, A., Op. Cit., p. 29.

Segal's review of direct service programs initiated by local parent associations indicates a similarity of service elements. Most organizations sponsored preschool nursery classes, educational and social training classes for young adults, summer day camps, adult recreational groups, work activity centers or sheltered workshops, and parent educational and counseling programs.²⁵ The majority of the children and young adults attending these programs were classified as moderately or severely mentally retarded and came from middle income families.²⁶

As individual programs gained community recognition and credibility, the local organization would begin to attempt to have fiscal and operational sponsorship transferred to a public agency; usually, to the public schools. Wolfensberger has hypothesized that there are three stages in the evolution of voluntary associations for the mentally retarded.²⁷

In stage one, parents of young retarded children, concerned that education was not available to their children, started classes, often in church basements. More parents joined and gradually they realized that a range of services would be required.

Stage two occurred when associations had initiated a number of new types of services and began to turn to public funding for the

²⁵Segal, R., Op. Cit., pp. 37-44.

²⁶Ibid., pp. 86-87.

²⁷Wolfensberger, W., "The Three Stages in the Evolution of Voluntary Associations for Retarded Persons," article in Mental Retardation News, Jan., 1973.

necessary long-term support. Associations either used public monies to operate their own services or turned over the services to public bodies.

At this stage, parent associations frequently experienced periods of extreme difficulty and trauma regarding decisions of relinquishing control over programs.

While a number of local parent membership associations are still involved with providing direct services, the trend throughout the country is for tax-supported and private non-profit community agencies to be responsible for these functions.

It is at this point, says Wolfensberger, that associations are likely to enter into his hypothetical "stage three," where they recognize the need for more systematic "change agency" and organization. Their role now becomes one of monitoring public financial programs and developing program safeguards such as evaluation of the quality of services and fixing legal mandates for service upon specific public bodies.²⁸

The self-organized parent associations played a unique role in demonstrating during the 1950's and 1960's that retarded children and young adults could benefit from a range of services and that it was the basic responsibility of local communities to provide these services.

The associations for retarded children throughout the United States are embarking on a new, but equally relevant role. As our

²⁸Ibid., p. 2.

society becomes more accepting of the principle of local, state, and federal aid for the care of the handicapped, local associations should begin to broaden their range of interests and activities. Social action focus should be expanded to include the support of issues not immediately related to the retarded but affecting them such as perinatal care, adequate nutrition, early social and cultural stimulation, individualized education, and protection of legal rights.

CHAPTER V

ORGANIZATION OF COMMUNITY PROGRAMS FOR THE MENTALLY RETARDED

INTRODUCTION

The growing awareness of the right of the mentally retarded citizen to remain in his home community is accompanied by an equally increasing demand for community programs. A sense of urgency accompanies the determination to have appropriate services and facilities available for all levels of retardation and all age groups in a more balanced pattern of distribution.

With the rapidly changing social trends of our time, community agencies, public and private, are being pressed to re-evaluate their conceptions of their proper functions. Examples may be seen in the increased activity of tax-supported agencies in providing social services and welfare benefits. In some cases environmental changes do away with the need for services which are presently available and in other cases create the demand for new services.

The nature of an existing agency program at any given time is a function of many different factors including the composition and distribution of the population within the community, the current social philosophy, and the apparent needs of the client population. Ideally, the programs of social welfare organizations should adjust to the changing needs of the peoples they serve.¹

¹Kaplan, H., Program Innovations in Community Agencies, Austin, Texas, The Hogg Foundation for Mental Health, 1970, p. 5.

Nonetheless, structures have a tendency to solidify. Often there is much variability in the willingness of community service agencies, both public and private, to modify their programs in response to changing circumstances.² The rapidly changing philosophy and concepts regarding treatment modalities for the mentally retarded, brings with it an urgency for effective, realistic, and practical planning in the development of future services and facilities for these citizens of the community who have special needs.

It has been pointed out by Adams that mental retardation is not a problem area around which it is possible to mobilize the interests and resources of a total geographic community since "the incidence of 'identified' retardation is necessarily limited to a minority of individuals and families."³ On the other hand, community program planners need to be aware of the broader implications of the problems of retardation. For instance, the family that is burdened with the continued care of a severely retarded child or adult, and does not have access to outside help, is liable to find its psychological and social stability undermined by the resulting pressures. If the mother breaks down, she may need treatment in a mental hospital, the retarded individual will need emergency surrogate care, any other children in the family will have to be provided for, and so on.

Community program planning for the mentally retarded, therefore, needs to be viewed from the circumscribed set of problems related to

²Johns, R., Confronting Organizational Change, New York, Association Press, 1963, p. 28.

³Adams, M., Mental Retardation and Its Social Dimensions, New York, Columbia University Press, 1971, p. 248.

individual malfunctioning, and also from the broader secondary effects of retardation upon normal individuals. While the prime objective of all programs for the mentally retarded is to provide opportunities for each individual to attain his fullest potential, the overall goal of community organization must be to diminish obstacles to social development and functioning that the disabling condition imposes upon both the retarded themselves and their families.

There is also, another element to be considered in the planning process which is extremely important although not directly related to the needs of the retarded individual or his family. Because of the chronic nature of retardation, the normal community will need to acquire an accurate understanding of this handicap, its social etiology and manifestations, so that, in addition to the development of formalized services, the community will develop an informal system of interaction with the retarded. In this manner, the "isolation" pattern of existence, so predominant amongst the retarded, will be broken into and their capacity for normal involvement in the community will be strengthened.

GUIDELINES FOR COMMUNITY PLANNING

It has been generally stated that planning of services and facilities is a process through which all factors relating to the needs of the mentally retarded are identified and considered as an integrated whole.⁴ From its broadest viewpoint, the process must

⁴ibid., p. 252.

define the nature and scope of the problem as manifested locally; it must be aware of the resources available; identify the problem areas needing solution; and enlist the services and skills of professional and community leaders.

The planning efforts specific to the development of community services for the mentally retarded must be realistic, timely, and most important, productive of tangible results. Consideration must be given to the cultural and economic patterns of the area to be served, the limitations of existing and anticipated community resources, and the degree to which acceptance and support can be expected.⁵

Once these basic determinations have been made, the recommended planning process⁶ should take into account the following principles:

1. Any agency or organization, governmental or voluntary, which is considered to have a significant potential for contributing some element to the overall program for the retarded should be encouraged to participate in the planning process.

2. Consideration should be given to the utilization of general community services and facilities to the fullest extent possible. It has been noted that many of the medical, health, and social service needs of the retarded are similar to those of the general population, therefore, maximum use should be made of general services which meet such needs.

⁵Orzack, L., et al, Process of Change: Goals, Obstacles and Results, Bridgeport, Connecticut, The Kennedy Center, 1970, pp. 5-9.

⁶Public Health Service Committee on Planning Facilities for the Mentally Retarded, Planning Facilities for the Mentally Retarded, Washington, D. C., U. S. Department of Health, Education, and Welfare, 1964, pp. 5-14.

3. All potentially influencing factors, such as social and economic trends within the community, should be carefully considered. Practical and realistic planning cannot be done in a vacuum. Many aspects of community life, such as shifts in population growth and age composition, patterns of commercial and industrial growth, and changes in land utilization, will affect the development and utilization of services and facilities for the retarded. Furthermore, it must be recognized that a shift in the program content of other health, education, and welfare agencies may strongly influence the demand for services for the retarded.

4. Adequate data should be developed to provide a base for projecting the extent, character, and location of services and facilities which will be needed. Existing services, and their location, should be identified. Data should be obtained regarding the number and distribution of retarded individuals, their ages, levels of retardation, and types of services needed. In addition, the data should provide information regarding the potential for expanding and upgrading existing services and facilities, as well as information regarding efficiency and equality of existing programs.

5. Consideration should be given to the development of programs for the prevention of mental retardation. Through preventive programs many individuals can be spared much mental and physical damage, and their families will be spared great emotional stress. Consideration needs to be given to such programs as maternal and child care in "high risk" areas, early diagnosis, genetic counseling, and more effective methods of case finding.

6. Planning should be based on the total and complete needs of the mentally retarded rather than on the availability of financial support. However, priorities should be established for meeting these needs on both a short-range and long-range basis. Factors influencing high priority services should include urgency of needs and the feasibility of meeting these needs quickly. Feasibility, in turn, is influenced by available resources, funds, personnel, leadership, and most importantly, public acceptance. It is important that long-range goals do not become compromised through the implementation of hastily conceived and poorly structured programs.

7. A detailed evaluation of the effectiveness and efficiency of existing services and facilities should be an integral part of all planning activity. In addition to determining whether the facilities and programs are meeting all prescribed standards for accreditation, licensure, and grants-in-aid regulations, the evaluation should cover such essentials as cost-effectiveness of program, adequacy of staff and efficiency of management.

8. To the extent appropriate and feasible, services and facilities for the mentally retarded should be planned so as to be readily accessible to the population to be served. Daily travel time for the retarded individual should be kept to a minimal level, and residential facilities should be located where families may visit easily. Wherever possible, service facilities should consider future population trends and growth patterns and projected development of transportation patterns.

9. Providing for adequate professional personnel and continuing inservice staff training is an essential part of the

community planning process. The potential for productive interaction between facilities for the retarded and systems of higher education should be investigated and cultivated. Long-term interrelationships between college and university faculty and service agency personnel will contribute notably toward the primary purpose of bringing the best possible service to all the retarded in the community.

10. Finally, in order that the planning process remains effective and responsive to changing needs, the planning group should develop procedures to evaluate their progress on a continuing basis. By the process of continual evaluation, overall needs will be kept in constant focus and changes can be made whenever justified. To guard against any tendency toward rigidity, the planning group should make full and continual use of resources which develop new knowledge regarding more effective means of meeting the needs of the mentally retarded.

In summary, effective planning cannot be done in isolation. Essentially, planning should be viewed as an attempt to analyze the social profile of the community so as to develop a cooperative working relationship with the subsystems in the community which can offer the strongest potential source of help.

Within the context of the aforementioned principles, community planning affords opportunities for developing greater awareness of the needs of the mentally retarded and for stimulating the action necessary to achieve a comprehensive pattern of services for them.

DEVELOPMENT OF COMMUNITY SERVICES
FOR THE MENTALLY RETARDED IN HOUSTON, TEXAS

BACKGROUND

The first evidence of any formal service being provided for the mentally retarded in Houston, Texas was in 1926 when one class for the mentally retarded was opened in the Houston Independent School District.⁷ There are no accurate statistics to indicate the extent of mental retardation in Houston at that time; however, the projected population of persons under 20 years of age was 95,000. By applying the average three per cent ratio factor, it could be hypothesized that 2,850 individuals presumed to be mentally retarded to some degree were present in the Houston area.

The State of Texas gave official cognizance to the problem of mental retardation when it established a State Colony for the Feeble-minded under an act passed by the 34th Legislature in 1915. At that time it authorized the construction of a 60-bed unit. In 1925 the name of the State facility was officially changed to the Austin State School, and by 1932, the resident population had grown to 1,000. In 1934, to reduce the growing waiting lists, the Austin State School Farm Colony with a bed capacity of 76 was established as a branch of the Austin State School. The population of both of these institutions

⁷Community Council of Houston and Harris County, Child Welfare Study, Houston, Texas, December, 1963, p. 2.

continued to grow, and by 1944, they housed 2,450 mentally retarded individuals.⁸

Not unlike other states in the nation during this period, the official Texas "answer" to retardation tended to be institutionalization or official ignorance of the problem. The first official legislation to grant public school special education opportunities to mentally retarded children was only passed by the 51st Legislature in 1952. By 1950 a total of seven classes for these children had been established by the Houston Independent School District and in 1952 there were a total of twenty-one classes for the mentally retarded.

HOUSTON COUNCIL FOR RETARDED CHILDREN

In the same year, 1950, a handful of parents organized the Houston Council for Retarded Children. Less than a dozen parents with mentally retarded children whom they did not wish to institutionalize, but for whom services in the community were not available, met together to discuss their common plight. In a sense, this represented the beginning of "community organization" for the mentally retarded in Houston. The objective of the group was primarily to stimulate the interest of the public in the needs of the mentally retarded and to obtain services in the local community for their own children. Parent members associated with the group at that time recalled the fervor of this early period when all concerned with the group felt themselves

⁸Texas Research League, The Program for the Mentally Retarded, Austin, Texas, 1955, pp. 12-13.

identified with a moral crusade to rescue their children. Meetings would run late into the night and would often be very fiery.⁹

During the next five years (1950-1955), as membership in the Houston Council for Retarded Children grew, a small day school for ten severely retarded children was established, along with a Boy and Girl Scout Troop and a five week summer daytime recreation program. A few professional workers were employed on a part-time basis, but, in the main, parents volunteered their time, effort, and skills to the operation of these programs. By 1956, as public awareness of this problem increased, a total of thirty-nine classes for the mentally retarded had been established in the Houston Independent School District. Four of these classes were for the accommodation of the trainable school age child, and the remainder for the educable retarded child. In accordance with the school policy of that time, all classes were racially segregated.¹⁰

During that same year, 1956, the Community Council of Houston and Harris County, an organization concerned with the broad aspects of community planning in the areas of health, education, and welfare, became interested in the needs of this group of handicapped persons and proceeded to look at the problem on a community-wide basis. The results of their study, and subsequent recommendations, laid the groundwork for the future development of this self-organized parent organization.¹¹

⁹Interviews with organizing members of the Houston Council for Retarded Children.

¹⁰Community Council of Houston and Harris County, Interim Report on the Council for Retarded Children, Houston, Texas, 1957, pp. 7-8.

¹¹Ibid., pp. 12-15.

in conjunction with the recommendations of the Community Council, the Houston Council for Retarded Children reorganized their structure to establish a Board of Governors which was not composed totally of parents of retarded children, as had been the case previously. Instead, they invited to membership on the Board some of the most powerful and influential leaders of the lay community. Backed by this new source of talent and support, the Council soon began to enjoy a high degree of visibility within the community. A reconverted mansion was turned over to them for the operation of service programs. An advisory committee of professional persons comprised of individuals from related fields, namely medicine, education, and rehabilitation, was formed. Also, a professionally trained executive director was employed for the purpose of developing and coordinating a total program of services for the mentally retarded in Houston.

In summarizing the early years following its establishment, the Houston Council for Retarded Children, a small self-help group, through the intensity of its emotional involvement made some minor gains in relieving some of the guilt feelings of the parents, in receiving recognition from some voluntary community agencies, in providing a few otherwise unavailable services for noninstitutionalized mentally retarded children, and in eliciting a measure of sympathetic press attention for the problem in various local papers and radio and television broadcasts.

At its beginning the Council represented mainly parents of trainable or otherwise retarded children who were being kept at home and for whom there were insufficient community services available.

The Community Council of Houston and Harris County, together with a strong and influential lay Board of Governors, was instrumental in making the organization more professional by insisting that it employ a full-time director to gain recognition and a share of general funds available through the United Fund. As a result, the organization grew and began to assume a dual role, not usually associated with voluntary interest groups, of combining agitation for government-provided services with its own provision of services. This early period was also marked by numerous political activities which were focused mainly on influencing state legislation.

In early 1957, a survey of existing services revealed that, aside from the limited number of classes operated by the public school and the small day nursery class and summer recreation program being operated by the parent group, there was virtually nothing else available for the retarded person living in Houston. Based upon the findings of this survey and numerous interviews with parents of retarded children and community workers, a plan which delegated the responsibilities of public and private agencies in the community in order to meet the total needs of the retarded was recommended and approved.

The plan established a priority listing of needed services under two major headings; public responsibility and private responsibility. The existing legislation provided only for the acceptance of "educable" children of school age into public school special classes. Retarded persons of all other ages and levels were, at that time, the responsibility of the private community agency. Consequently, a "try, sell, and supervise" strategy was incorporated into the plan.

In essence, the Council would establish a program, demonstrate its efficacy, and attempt to attract public funds for its support or turn the program over to a public agency.

In accordance with this prescribed plan, services to the retarded of Houston were initiated. Frequent meetings were held with staff and lay members of the Community Council, Houston Independent School District, Office of Vocational Rehabilitation, Welfare Department, and Council Board and Advisory Committee in order to review progress, coordinate programs, and establish additional areas of need.

RESULTS OVER A FIVE YEAR PERIOD

By 1961, over a five year period, the Houston Independent School District had expanded the number of their classes from 39 to 102, and a total of 1,553 pupils, educable and trainable, were attending these classes. A comprehensive diagnostic clinic had been established at Texas Children's Hospital for the purpose of early diagnosis and evaluation of retarded children between the ages of one through fourteen. The Houston Office of Vocational Rehabilitation, which previously had shown only minimal interest in this handicapping condition, had designated one counselor to be concerned specifically with the training and rehabilitative needs of retarded adults. A private residential facility for non-ambulatory profoundly retarded children had been opened, and a parent volunteer had been given a desk in the offices of the County Judge to assist parents who were making application for state school placement.

During this period, the direct service programs of the Houston Council for Retarded Children had been expanded. By 1961, the Council had expanded its preschool classes to accommodate fifty children; established classes for thirty retarded children of school age, who were not eligible for acceptance into public school special classes because of behavior defects; established the first Sheltered Workshop in the state for thirty trainable retarded adults; expanded its recreation services to include weekly social activities and residential summer camping; added a social worker and psychologist to the staff for the purpose of providing testing and family casework services; and broadened its public information and education program to include a monthly newsletter which was mailed to all community agencies, public and private, to key community political and lay leaders, as well as to all parents and professional workers in the community.

DEVELOPMENT OF THE HARRIS COUNTY CENTER FOR THE RETARDED, INC.

In the latter part of 1961, the Community Council was asked to reexamine the services being provided to the mentally retarded of Houston and to determine whether they were adequately meeting the needs. Concurrent with this request for an analysis of services being provided for the retarded, the Board of Governors of the Houston Council requested, from the United Fund, permission to hold a large capital fund drive for the purpose of building a modern, scientifically designed community center for the retarded. The request was accompanied by

documented evidence pertaining to the inadequacy of the then current facility due to program expansion and growth.¹²

At the same time, the Assistant Superintendent of the Houston Independent School District in charge of special services was invited to study the public school special education program with respect to future needs. Officials of the school district authorized the study and employed three nationally recognized consultants in the field of special education to assist with it.

If the decade of the 1960's was the climactic era in the nation for mental retardation, then 1962 was surely the curtain-raising period in Houston. Throughout this year, and during the first half of 1963, lay and professional committees were actively engaged in studying the present and future needs of the mentally retarded from a diversity of viewpoints; the community agencies, public schools, and residential institutions.

The studies were coordinated by the Community Council and included a projection of population increase to 1970. The cumulation of evidence revealed that:

1. The present programs of service, both public and private, were providing service to approximately 30% of those retarded persons and their families needing these services.

2. The Houston Independent School District would need to project a 50% increase in current special education services in order to meet future demands.

¹²Records of personal correspondence to the Director of the United Fund from the Chairman of the Board of Governors, Houston Council for Retarded Children, April 29, 1961.

3. There remained a great void in residential care facilities, public or private, for the retarded in the Houston community.¹³

Accordingly, the Houston Independent School District proceeded to review the recommendations made with respect to expansion of classes and quality of instruction and, by 1966, had increased the number of class units for educable and trainable retarded children to 244.¹⁴

Further, the parent members of the Houston Council for Retarded Children and key Board members, in conjunction with the Texas Association for Retarded Children, petitioned the State Legislature to consider the need for residential facilities in the Houston-Harris County area. This finally resulted in the passage of a bill by the State Legislature for the construction of a State residential school for the mentally retarded in the upper Gulf Coast area (Richmond State School, located 30 miles from Houston, is now in operation).¹⁵

Finally, the Board of Governors of the Houston Council for Retarded Children petitioned the Houston City Council for, and was granted, a five acre tract of land in the center of Houston upon which they proposed to build a unique center embodying all services required for the mentally retarded other than residential care.¹⁶

¹³Community Council of Houston and Harris County, Report on the Study for Retarded Children, Houston, Texas, March, 1963, pp. 8-10.

¹⁴Community Council of Houston and Harris County, A Coordinated Plan for Service to the Mentally Retarded in Houston, Texas, Houston, Texas, September, 1966.

¹⁵Ibid., p. 6.

¹⁶Ibid., p. 7.

THE HARRIS COUNTY CENTER FOR THE RETARDED, INC.

During the intervening years, 1962-1965, while considerable attention was being given to the architectural conceptualization of a campus-type facility geared toward a total rehabilitative purpose for mentally retarded children and adults, thought was also being given to the reorganization of the Houston Council for Retarded Children.

In order that the boundaries might be expanded to serve mentally retarded children throughout the whole of Harris County, it was decided to divide the existing organization (Houston Council for Retarded Children) into two separate entities. One organization (Houston Association for Retarded Children) was created as a "membership" organization with the primary purpose of promoting parent interest in educational and legislative needs. The second organization (Harris County Center for the Retarded, Inc.; H.C.C.R.) was established for the purpose of developing direct service programs and research and training efforts for the mentally retarded of Harris County. It was structured as a private, non-profit community service agency with a lay Board of Governors to direct its affairs. Key community leaders were invited to serve on the Board along with representatives from each of the parent-membership associations in Harris County. In addition, a Professional Advisory Committee, comprised of leaders in the fields of medicine, psychology, higher education, health, and rehabilitation, was established. The structure also called for an Executive Director as chief administrator to implement the policies and programs of H.C.C.R. as determined by the Board of Governors.

The purposes of the new agency were stated in the By-laws as follows:

- a. To promote the welfare of and assist in the mental and physical development of all mentally retarded persons.
- b. To cooperate with other groups and organizations with a similar purpose, and, in particular, to cooperate with, assist and support in any manner practicable, the Houston Association for Retarded Children and similar organizations in Harris County, Texas.
- c. To further the advance of all ameliorative and preventive study, research and therapy in the field of mental retardation.
- d. To develop a better understanding of the problems of mental retardation by the public.
- e. To further the training and education of personnel for work in the field of mental retardation.
- f. To encourage, advise and aid parents in the solution of problems that pertain to the welfare of the mentally retarded.
- g. To operate one or more schools, clinics, diagnostic centers, or sheltered workshops for the benefit, training, and education of the mentally retarded.¹⁷

By the closing months of 1966, the new scientifically designed comprehensive center for retarded individuals in Harris County, and in fact, the largest non-institutional center in Texas, was ready to commence operations. Its six buildings contained a total of 70,000 square feet wherein health, educational, vocational, psychological, social, recreational, and dental services could be provided for mentally retarded individuals of all levels and ages. In addition, a Student Union Building contained a cafeteria, swimming pool, gymnasium, and auditorium.

¹⁷Board of Governors, "By-Laws," Houston, Texas, Harris County Center for the Retarded, Inc., August 24, 1965, Article 1, Section 2.

During the subsequent years, 1967-1973, additional programs and facilities were established under the aegis of H.C.C.R. Four day care and training centers were established for mentally retarded children of working mothers; contracts, for the provision of special programs, were entered into with the Houston Independent School District and other school districts within Harris County; in cooperation with the Harris County Mental Health and Mental Retardation Authority, a series of community residences were established along with day care and educational programs; contractual agreements were made with Texas Rehabilitation Commission for specific rehabilitative services to adult retarded persons; programs for children from the poverty areas were established in conjunction with the State Department of Welfare; and arrangements were made with the University of Houston to provide field experience for students preparing to enter the education profession as special education teachers.¹⁸

Currently, the Harris County Center for the Retarded is having constructed a six-story community residential facility adjacent to the present campus. It is the intention of H.C.C.R. to develop a residence hall which will enable mentally retarded adults to live and work productively in a normal manner with dignity and self-sufficiency in their own community. The residence hall will serve 200 mentally retarded men and women and will represent a sound economic, as well as human,

¹⁸Harris County Center for the Retarded, Inc., Annual Report - 1972, Houston, Texas, 1972.

Investment. Plans call for this project to be completed by the middle of 1974.¹⁹

The report of The President's Panel on Mental Retardation (October, 1962) states:

This report is predicated on a strong conviction that the mentally retarded person should be served with as little dislocation from his normal environment as is consistent with the special character of his needs. Those needs should be met as close to his home as possible and in such a way as to maintain his relation with his family and peers.²⁰

The report further states that:

Among the services which may be offered in an area center are: referral, diagnosis, counseling, day care, special medical care, recreation, halfway and self-government houses, and workshops and adult activities in which both day and resident clients participate.²¹

It is evident that the development of community service programs for the mentally retarded of Houston has followed, to a great degree, the guidelines set forth by the President's Committee in 1962. Because of the "centralized" character of the H.C.C.R. system, there are fewer opportunities for the interruption of the "continuum of care" concept. By its high visibility the Center fosters a continual community awareness of the retarded and their capacity to become well integrated within the community. Finally, as a community service agency, it has continually attempted to adjust its programs to the changing needs of the peoples it serves.

¹⁹Ibid., p. 12.

²⁰The President's Panel on Mental Retardation, National Action to Combat Mental Retardation, October, 1962, U. S. Government Printing Office, Washington, D. C., p. 144.

²¹Ibid., p. 92.

CHAPTER VI

SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS

SUMMARY

The purpose of this study was to identify, from an historical and developmental perspective, the major factors which had a significant effect upon public policy and treatment services for the mentally retarded. A further objective was to illuminate the different social philosophies underlying the decision-making process in this problem area and the subsequent social programs these gave rise to. The final objective was to identify the service-model trends now emerging, with regard to the mentally retarded, which will provide insight as to the methods communities of the future will utilize in coping with this "surplus" population.

Residential Care

Since the evolution of treatment programs for the retarded began with residential care, a comprehensive review of the historical development of public institutions was made.

The primary goal of institutions founded in the 1850's was based upon the premise that deviants could be made undeviant. The institution of that period was viewed as a temporary boarding school where retarded children could be trained and then returned to their own homes or to regular school. Interestingly enough, these mid-nineteenth-century

institutions were located in the center of the community, where they were a part of society. But difficulties were soon encountered with this model. It did not provide for all the retarded needing residential services. There were those who were not capable of returning to the community. Others, who were ready for return to the community, had no place to live. Furthermore, the public had been led to expect "cures" for mental retardation which were unrealistic and, eventually, unrealized.

Between 1870 and 1880, with the apparent inability of many retarded persons to make their way in the community, once hopeful attitudes changed to attitudes of pity and maudlin sentimentality. This was the period during which institutions strove to "protect" the deviant from the undeviant. Schools became asylums. Institutions became permanent custodial shelters where, in bucolic settings, "God's innocent ones" could be cared for. Stemming from this "pity" period came the misconceived notion that all retarded were happiest with their own kind. A mythology that has unfortunately flourished unquestioned for more than a century.

This attitude of "pity and protectiveness" established a care and treatment model which was to set the trend for future service delivery patterns. It not only resulted in a misdirected effort which led to massive isolation and segregation of individuals, but also opened the way for a period of dehumanization from which we have not yet entirely emerged.

During the early part of the twentieth century, a number of surveys, studies, and tests, masquerading as scientific instruments, resulted in the retarded being charged with responsibility to a large

extent for many, if not all, of our social problems. Since the retarded individual was now regarded as a menace to society, the programmatic goal became one of protecting the undeviant from the deviant. All kinds of dehumanizing practices were introduced into institutions: exploitation of the retarded as a worker in the institution; stripping the retardate's environment of all amenities and comforts so as to reduce costs; increasing the size of institutional populations to 3,000 and 5,000; locking retardates into buildings and rooms; and infringing grossly on their civil and human rights.

Federal and State Legislation

A second factor which had great impact on the fortunes of the mentally retarded was the interest shown by the Federal and state government in this segment of our population, and the subsequent legislative and programmatic activities that followed. The Federal programs of legislation and funding have been the result of a combination of many forces interacting over many years, some steady, some transient, some central, and some incidental.

The history of the early activities of the Children's Bureau indicates that there was some Federal interest in mental retardation as long as half a century ago. Acting primarily in an advocate role, the Bureau provided a consultancy service to state departments of health and a clearing house of information on trends in the care of the mentally retarded child.

It was not until the advent of the Kennedy Administration (1960-1963), however, that massive Federal legislation and funding

activity on behalf of the mentally retarded took place. The legislation that was enacted during this period, the global recommendations of the President's Panel on Mental Retardation, and the subsequent activities of state governmental bodies, resulted in the first nationwide effort to establish a process of comprehensive mental retardation planning.

The enacted legislation was characterized by two significant features which are dominant in present day legislation pertaining to the mentally retarded. One was the emphasis placed on preventative measures through an extension of health services to mothers and children at risk, which carried the admission that retardation was closely connected with poverty and adverse social circumstances. The other was the provision of means for stimulating services at a local level but on a nationwide scale through Federal Grants.

More recently, the judiciary branch of Federal and state government has begun to take an important role in the development of appropriate services for the mentally retarded. Throughout the United States, the courts are giving consideration of the basic rights of the mentally retarded, not only from the standpoint of their collective rights and those of their families, but also from that of the individual rights of the retarded person as a human being.

Voluntary Parents' Associations

A third component that had a direct bearing on the treatment patterns developed for the mentally retarded had to do with the formation of self-organized groups of parents of retarded children.

The early self-help movement began in the 1930's as a spontaneous reaching out of parents to one another, eager to share their similar problems and concerns. The movement flourished and, in 1950, the National Association for Retarded Children was founded. The establishment of NARC as a nationwide organization of parents and friends of the mentally retarded had a profound effect upon the general welfare of this minority population. By coming together publicly, the families of the retarded put their sense of shame behind them and presented the needs of their children as a social rather than merely a personal problem.

Through this federated-type organization, parents were able to command public attention - which they proceeded to do through national magazines, radio and television network broadcasts, special publications, and direct representations to public officials at every level of government. Hundreds of local units, and later scores of state associations, provided the vehicle for thousands of individuals to express their concern and to motivate community response.

The impact of this movement was felt primarily in subsequent government action and comprehensive community planning. A secondary impact was made in the area of public awareness and concern for the mentally retarded.

Community Agencies

Finally, in order to ascertain the effect that these aforementioned factors had upon the development of community services for the mentally retarded, the evolution of a self-organized group

(The Houston Council for Retarded Children) and the subsequent development of community programs through a community agency (The Harris County Center for the Retarded) was studied.

The early efforts of the parent self-help group (H.C.R.C.) laid the groundwork for the future development of community services for the mentally retarded in Houston, Texas. It brought the problem of retardation to the attention of other voluntary agencies in the community, and established beginning programs that would enable the more severely retarded child to remain in the community.

The later formation of a separate community agency (H.C.C.R.) charged with the responsibility of developing direct service programs for the retarded in a county-wide area, led to the implementation of a well-rounded community program with significant intertwining of private-professional-governmental relationships.

CONCLUSIONS

A comprehensive review of the historical development of public residential treatment programs illuminates the fact that society's attitudes toward deviancy has been, and remains, the single dominant factor in shaping successive patterns of care for the mentally retarded, as they evolved in the United States.

Ignorance of the causes and nature of mental retardation, of the principles of multifactorial genetics, of the mathematical laws of probability, and even elementary principles of statistical sampling, resulted in conclusions and pronouncements that led to the passage of punitive sterilization laws and segregation practices.

Changing Patterns in Residential Care

Today, there is evidence of determined efforts to remove from residential services the dehumanizing, custodial practices of the past. Concerned parents, professionals, and governmental agencies are separately, and in concert, developing programs to effect change. To indicate that new concepts and new practices have come into the field, such terms as "residential services" and "residential facility" are replacing the formerly commonly used terms as "institution" and "custodial care."

"Residential services" imply a new concept in which the residential facility is an integral part of a complete array of services needed by the retarded during a lifetime. This is a different concept from the self-contained institutional care concept of the past. However, there are still relatively few communities in the United States today that can offer to the parents of a retarded child, particularly, a severely retarded or non-ambulatory child, any alternative for long-term residential care other than the large public, custodial-type institution.

The potential for effecting massive change is here. The professional workers in the field, and particularly the new breed of superintendents of public institutions, know a great deal about what should be done to improve services. New knowledge, both in and out of residential settings, is available on how to better educate individuals with mild to moderate degrees of retardation, how to shape their behavior and train even the profoundly retarded, how to reduce the need for bedfast care, and even how to deploy staff for optimal interaction.

Yet, despite all these hopeful possibilities, there still exist the massive unsolved problems of overcrowding, understaffing, and underfunding. It is evident that despite the gains made in public acceptance and sympathy toward the retarded, there still remains an unspoken attitude that mentally inferior people are somehow less than human, and less than worthy of society's concern.

Social Impact Of Legislation

Still, the thread of human concern and the sense of social responsibility for the retarded does manifest itself in the more recent (since 1963) programs of Federal and state legislation. The legislation enacted during the Kennedy Administration gave mental retardation a national context. It implied that such a prevalent and seriously handicapping condition could not be properly dealt with by local resources alone and needed Federal backing.

Further, the philosophical implications of this legislation are of significant social import: in providing care for the most disabled and least socially productive members of the nation, it implicitly laid down a concept of social welfare whereby the deficiencies of the weak and less well endowed should be the responsibility of the total society in which they live. This concept, which still has yet to achieve unqualified acceptance in the United States, has within it all aspects of community acceptance that can result in a full and satisfying life for each handicapped individual.

The legislation that has been passed to deal with the far-reaching and complex problems of mental retardation has indeed been

impressive. Current support, by all levels of government, while not extravagant is at an all-time high. Moreover, antipoverty programs, such as Headstart, and recent welfare legislation, now include assistance to the mentally retarded as well as other groups in need.

More significant, however, has been the recent attention given by the courts to the "rights" of the mentally retarded. Since 1970, more than 35 cases pertaining to the "rights" of the retarded were heard in courtrooms throughout the nation. While the overriding implication of these recent court decisions confirmed the right of equal access to educational opportunity for all children, other "rights," the right to treatment, the right to habilitation, were also affirmed by the courts. In going to the courts, exceptional citizens found a new forum to enforce their rights and perhaps create new rights. Litigation, while not a substitute for other modes of social action, has emerged as a potent lever with which to move society toward more equitable treatment of the handicapped.

Parents' Associations As Social Change Agents

In reviewing the historical approach to mental retardation and the subsequent changes that have occurred in the area of services for the retarded, it is evident that many of these changes were brought about by the direct intervention of the parents' associations.

The establishment of the National Association for Retarded Children in 1950 stimulated local and state organization efforts of parents of the mentally retarded. Further, it helped parents find each other and begin to replace their feelings of guilt with mutual emotional

support. It led also to an extensive program of public information and sensitization which brought the subject of mental retardation into the open.

Since the majority of the members came from white, middle-class families, the associations tended to use those social action strategies that were more in keeping with the normative values of the middle and upper middle class. These strategies focused more on the use of education and persuasion rather than on intimidation. This is reflected in their legislative and community demonstration programs which were particularly effective in the areas of special education, diagnosis and evaluation, governmental coordination and community planning.

Although parent associations did achieve impressive results on social change agents, there now appears a need for re-examination of their social action goals. During the 1950's and 1960's, local parent associations were heavily involved with the development and provision of community-based service programs, and the membership strongly identified with this role. Now that tax-supported and private community agencies are assuming the responsibility for direct service, community-based programs for the retarded, the local parent associations are finding it necessary to establish new goals with a wider social scope.

Indications are that future social action thrusts of local, volunteer parent associations, as well as the national association, will focus on a much broader range of interests. Activity will revolve around such crucial issues as the causal relationship between poverty and mental retardation, legal rights of the retarded, statewide systems of advocacy, and positive approaches to the prevention and alleviation of mental retardation.

RECOMMENDATIONS

The future, particularly the latter part of the present decade, has been portrayed as a time of rapidly accelerating technological and sociological change. A large number of people representing many fields of endeavor are currently in the process of prognosticating the direction and impact of change in the years ahead. The quest is for meaningful ways to respond to change. Only if we are alert to the dynamics of change, will we be able to direct our future planning for the retarded into a creative process that will aid in maximizing the human potential of this group.

As has been previously stated, the primary objective of this study has been to identify those trends that will significantly affect society's future treatment of the mentally retarded. Viewed as forecasts, they are significant only as they demonstrate the plausibility that some action will be taken. However, action, in and of itself, will not resolve the all-encompassing problem of mental retardation. A review of our past experiences must generate action that leads to growth; anything else is simple "activity."

It should also be noted that any forecast is, to some degree, influenced by one's individual experiences and biases. But, as Wolfensberger¹ suggests, we should not let our personal feelings, one way or another, stand in the way of attempts to assess reality. It is

¹Wolfensberger, W. "Twenty predictions about the future of residential services in mental retardation," Mental Retardation, 1969, Vol. 7, No. 6, pp. 51-54.

the opinion of the writer that anticipation of, and preparation for, likely future events is much more adaptive than an attitude of denial or impotent passivity.

Some of the trends are already beginning to emerge, and it will only be a question of when, not if, they will come into full fruition. The task of serving the handicapped is becoming more and more a concern of the public, and in the future, we can expect the government's assumption of responsibilities to increase rather than diminish. The fiscal burden of educating and rehabilitating our handicapped has been accepted as a national governmental responsibility, and is being handled at that level to a great degree. Currently, however, of each 1,000 dollars spent by the Federal Government, 350 goes for the Department of Defense, and 35 for education.² If this present state of disequilibrium with the way resources are allocated is to be remedied, it is imperative that professional and lay social action groups continue to press for a reorganization of priorities.

Societal Attitudes

Our society has come a long way from the days of gross human neglect. The myths, superstitions, and societal prejudices plaguing the retarded for centuries and resulting in their exploitation, extermination, and rejection are gradually dissipating. To be sure, they are being replaced with attitudes of a more positive, optimistic, and

²The Conference Board, A Look At Business in 1990, White House Conference on the Industrial World Ahead, Washington, D. C., U. S. Government Printing Office, 1972, pp. 45-50.

sympathetic nature. But, the full acceptance of the retarded person as a "citizen" of our society is still a long way off.

Recently (1973),³ a nationwide survey was made by a prominent national research firm to determine whether the National Association for Retarded Children should change its name. Respondents were asked to choose the name which they felt would portray the retarded most favorably from the following:

"National Association for Retarded Children"

"National Association for Retarded Citizens"

"National Association for Retarded Children and Adults"

Relevant factors, other than the sex of the respondent, were carefully noted, such as income, the regions of the country, city vs. rural, and age. None of these factors affected the general trend of the preference. It is significant that 75.2% of the respondents favored keeping the word "children" in NARC's name either alone or coupled with "...and Adults," while only 22.1% favored "citizens."

If this can be accepted as an indication of society's method of viewing the retarded, then the future trend of valuing the retarded person as a "citizen" of our society, with all of the guarantees of full and equal opportunity, is still a long way from becoming a reality. It is strongly recommended that every retarded person be provided with the opportunity to unfold his personality and develop his potentialities for his own sake and for the benefit of society. Only as each retarded

³News Article, "Survey Reveals Opinions on Name Change," Mental Retardation News, published by NARC, Vol. 22, No. 7, September, 1973, pp. 1 and 11.

individual attains full respect and value, will society realize and fulfill its obligations in establishing the kinds of community resources that will more completely meet their needs.

Social Action

The recent history of public policies that directly and indirectly affect the welfare of the public-at-large has shown evidence of a great deal of social change. Important to the welfare of the retarded has been the national efforts to eliminate poverty as a social problem and condition in our country. Measures are presently being developed to protect the economic security of handicapped individuals and needy families through the establishment of various programs of security and income maintenance. For example, as of January 1, 1974, new Federal regulations (P. L. 92-603) will guarantee a monthly income of \$130 for all aged, blind, and disabled persons.

As this trend continues it will be particularly meaningful to the retarded, whose maximum efforts represent minimum productivity. Social insurance programs will need to be expanded, however, to afford adequate protection against all future hazards and risks for the retarded individual. Government will have to take greater responsibility in public financing of human resource programs in the form of public services that emphasize the sense of common need and universal availability through entitlement rather than through favor. These public services should include housing, education, rehabilitation, health, employment, and income security programs.

If the preventative aspects of retardation are to be enhanced significantly, future social action thrusts must be directed at target and key problems; such as hunger and malnutrition, mothers and children at high risk, family planning, and early intervention. There is ample evidence now at hand (Heber, 1970; Heber & Garber, 1972; Kirk, 1958; Caldwell, 1970) that substantiates the positive effects of early intervention and early stimulation programs. They need only to be implemented on a nationwide scale in order to prevent cultural-familial mental retardation.

Patterns of Service Delivery

Serious consideration must be given to greater coordination and synthesis of traditional and new programs serving the retarded. Program and policy development will have to include broad community participation and coordination on a state and regional basis. In an effort to achieve adequate financial support, and to eradicate duplication and fragmentation of services, many service organizations and agencies, at the national, state, and local levels will need to merge. The comprehensiveness and effectiveness of services for the retarded will be more adequate and responsive to individual and community needs only as these adjustments are made.

An illustration of this merger trend at the Federal level is the recent incorporation of the Vocational Rehabilitation Administration with four other agencies to become the Social and Rehabilitation Service. This new organization was then placed under the single leadership of the Department of Health, Education, and Welfare.

At the national level, one can note an increased cooperation among the many large voluntary associations dealing with the handicapped. Recently, (August 1973) the national leadership of the Epilepsy Foundation of America, the National Association of Retarded Children, and United Cerebral Palsy Association announced their willingness to seek to develop cooperative efforts for joint action in specified areas.⁴

While discussion regarding formal merger was not part of the agenda, such possibilities as the sharing of office space, joint public information and public education efforts, and closer coordination regarding planned activities concerning legislation were carefully examined. It is entirely probable that there may be a fusion of these organizations in the near future and, since many of them are involved in similar goals, this type of consolidation may be desirable.

Many changes will also need to take place, at the local level, within voluntary parent associations. As the trend develops for tax-supported agencies to be responsible for direct services, parent associations should assume greater responsibility for the monitoring and evaluation of these services and programs. They must also demonstrate a greater interest and involvement in the broader aspects of community problems such as poor housing, health, or unemployment, since it is now realized that these factors directly affect the mentally retarded and their families.

As in the past, legislative activity and public education should continue to be vital functions of local parent associations. However,

⁴News Article, "Summit Meeting Held by UCP, NARC, EFA to Discuss Cooperation in Mutual Problems," Mental Retardation News, published by NARC, Vol. 22, No. 7, September, 1973, p. 3.

their social action focus must be expanded to include the support for issues not singularly related to the retarded. Some local units are currently involved with other community agencies in joint projects involving poverty areas. Attempts are being made to involve low-income families in action-oriented groups so as to provide them with effective mechanisms for coping with their many problems.

Since a strong membership base is essential to the continuing strength of local associations, much more energy will need to be expended on the recruitment of parents of retarded children from low socioeconomic groups and non-parents. The present membership now realizes that a community that is permitted to be complacent about problems of poverty, housing, and education can develop equal insensitivity to the needs of the mentally retarded.

Today, there is a strong emphasis toward making provisions within the local community for as many retarded individuals as possible. As this trend continues, it will have a profound effect upon the character and goals of residential institutions. Realistically, it must be acknowledged that our society will continue to segregate certain groups of individuals and put them into institutions. But it is evident that the basic rationalizations justifying this practice are being modified.

While more state-supported institutions are being constructed, they must be built smaller and more strategically located within urban communities. Institutions will need to be increasingly integrated into a continuum of community services with greater flexibility for movement

within the entire system of public and private agencies. More emphasis will have to be placed on short-term care with a view toward utilizing other services available within the community. Although the resident population is generally becoming younger and more severely retarded, a greater effort must be made to direct major programming efforts toward normal living patterns for all residents.

Community Planning

The needs of the retarded change with the advancement of knowledge, the evolution of social life, and the changing aspirations of people. Community planning efforts must be responsive to these changes, otherwise service delivery systems will fall back into sterile habits of institutional self-perpetuation that serve no one but the agencies themselves.

Planning in isolation should be regarded as a practice of the past. In the future, community planning efforts will need to be measured against the criteria of the total service delivery system's responsiveness to community needs, and by its own ability to respond to the needs of individuals, mentally retarded or otherwise.

Effective community service delivery systems for the retarded must have a sufficient array of components, actually present and operative, to meet the array of needs known to exist. If the full array of needed services are to be extended to the retarded so as to strengthen their ability to remain in the community, there will need to be greater coordination of services, less fragmentation, and increasing involvement of the consumer.

Day care, foster care, homemaking, housing, family counseling, to name a few, will need to be viewed as typical rather than occasional services, and be fully incorporated into the network of services available. Expressions of good will and intent, enabling legislation, tables of organization, and even buildings and staff are fruitless unless actual elements of service are available to the persons who need them, when they need them.

In addition, as funding sources become more restrictive, public and private community agencies must be required to fully account for the impact they allege upon the lives of their clients. Accountability should relate to such factors as availability of services; adequacy of benefits; efficiency in administration; continuity and dependability of program; quality of services; respect for consumers' wishes; and systematic provision for hearing consumer complaints.

Implications for the Future

During the next decade we will see the community assuming a greater degree of responsibility for the retarded individual. We have accumulated a vast amount of knowledge concerning the capabilities and human needs of this portion of our population. A proper and common utilization of this knowledge can readily lower the many barriers our society has inadvertently placed in the path of the retarded.

However, the fundamental basis for determining the future world of retarded individuals will rest on society's ability to conceptualize mental retardation as a humanistic issue rather than a moral issue;

for the real issue is the value we place on all of mankind. Only as this concept becomes a reality will there come a time when people will react to the retarded not out of fear, nor pity, nor even a misguided sense of charity, but with the simple realization that whatever produces a better behavioral adjustment for the individual also benefits society.

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