

SELECTED FACTORS INFLUENCING THE CARE AND TREATMENT
OF THE MENTALLY RETARDED PERSON: 1960 TO 1985

A THESIS
SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE DEGREE OF MASTER OF SCIENCE
IN THE GRADUATE SCHOOL OF THE
TEXAS WOMAN'S UNIVERSITY

COLLEGE OF NURSING

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DECEMBER 1986

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November 13, 1986
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To the Provost of the Graduate School:

I am submitting herewith a thesis written by Eleanor Woods entitled "SELECTED VARIABLES INFLUENCING THE CARE AND TREATMENT OF THE MENTALLY RETARDED PERSON: 1960 to 1985". I have examined the final copy of this thesis for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Master of Science in Nursing.

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Accepted

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This study is dedicated to my husband, Virgil, and my children, Ben, Julie, and Melissa. With their unconditional love, support, and encouragement this paper has been much easier than it might have been if they had not been in my life.

Remember always I love you each
for being my family.

ACKNOWLEDGMENTS

Completing this paper has been a labor of love and although it has but only one author's name, in actuality there is an extensive support group behind this researcher that must be acknowledged. I could not have asked for more encouragement, support and love than I received from those I am about to mention.

Firstly, my committee for their vigilance, endurance, and ever present faith that I would finish:

Dr. Anne Gudmundsen, for her innate insight in suggesting a subject that was so desperately interesting and has changed my entire perception of life;

Dr. Peggy Drapo, for her contagious enthusiasm, extensive knowledge base, and her devout recognition that humane treatment must always be the basis for any professional nursing intervention;

And Dr. Pat Mahon, for her guidance through the emotional maze into organization and factual presentation of this passionate issue.

Secondly, the people with whom I work and spend many hours a day with practicing our professions. They have supplied a complete extra support group to this researcher.

There are so many that to try to mention them all would be as extensive as the paper itself. There are a few though that I must single out to acknowledge:

Jane Gitter, my boss, for her understanding, patience, interest, and flexibility;

Kathy Mankinen, for her sympathico;

Margo Sands, for her mothering, and allowing me to vent and be disoriented at times;

And Lou Ashmore-Brashier for her calming understanding and reassuring ear.

Thirdly, I must thank those people who helped make the technical part of the paper possible:

Jean Halbert, the graduate secretary, for always having a calming smile, helping hand, and reassuring manner in helping me through the red tape, and making the process less intimidating and more manageable;

Marcia Willson, a fellow co-worker who edited this paper on her own time and whose interesting comments were invaluable when putting this paper together;

And Debbie McCord, my typist, who has been so patient, helpful, and professional with every plunk of the typewriter. She is by far the best arrow-follower I know. Debbie gets all the credit for making me look good in print.

Finally, I must once again thank my family.

My mother, Elmina Barrera Hagy, for instilling in me the need to keep going.

My children, Virgil Benjamin, Julie Renee, and Melissa Anne for doing more than what is usually expected of kids their ages and they did it well. They tolerated cold meals, no meals, late nights, skimpy help with their homework, . and prolonged promises that will now be fulfilled.

And, my husband, Virgil, for listening to all the complaining, coping with distant and depressed moods, and the many times he had to be both mother and father to our children.

To each and everyone of you, I gratefully acknowledge your individual efforts and support in helping me complete this study.

SELECTED FACTORS INFLUENCING THE CARE AND TREATMENT
OF THE MENTALLY RETARDED PERSON: 1960 TO 1985

ABSTRACT

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DECEMBER 1986

This study is a historical perspective dealing with the care and treatment people who are mentally retarded have experienced throughout history. The years chosen to detail were those where the greatest changes occurred, 1960 to 1985. The purpose of the study was to acquire a basic understanding of who these people are, what they have been subjected to, what changes have occurred, where are they currently in society, and what are the possible implications for their future care and treatment.

Data was collected, researched, and reviewed pertaining to the field of mental retardation. Selected factors were emphasized that influenced the care and treatment of people with mental retardation. Those selected factors were societal attitudes, legislation, litigation, normalization, and the role of the nurse. They were specifically

investigated to understand what impact they had on the field of mental retardation past, present, and future.

Sources of information were from published books, professional and lay periodicals containing newspaper clippings, documents researched and requested from the state capitol, and personal interviews with people involved in the field of mental retardation. These sources were compared and contrasted in the final compilation of this historical study.

A review of the general history of the field of mental retardation is initially presented. Secondly, a general history of mental retardation in the United States is covered, as well as its history in the State of Texas. Emphasis on the years 1960 to 1985 are presented in ten year blocks highlighting major changes during each decade. Major concepts related to the field of mental retardation are also addressed. Tables listing specific landmark decisions affected people who are mentally retarded are presented in a chronological format. Cognition of those historical aspects dealing with people who are mentally retarded and the long struggle they have endured to acquire their legal rights will hopefully permit professionals to make more humane decisions effecting their future care, treatment, and management.

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Humanness

Secretiveness is the handmaiden of anxiety
Anxiety is the enforcer of repression
Repressions is the progenitor of violence
Violence is the catharsis of madness
Madness is the escape from reason
Reason is the revolt from chaos
Chaos is the sperm of control
Control is the barbing of abuse
Abuse is the device of totalization
Totalization is the process of evil
Evil is the flight from humanism
Humanism is the hope for mankind
Mankind is the center of the being
Being is the life of the physical
Physical is the shell of the soul
Soul is the essence of the humanness
Humanness is the universal truth.

Burton Blatt

CHAPTER I

INTRODUCTION

As society prepares to embark on the final decade of this century, an introspective moment must be taken to consider the past and present before plotting our course for the future in the field of mental retardation. Parents for too long have heard much too often the familiar answers from professionals of institutionalization, of control and the attitude of hopelessness in regard to their children with mental retardation.

There have been many recent influences affecting the delivery of services to the mentally retarded. Changes in public attitudes, technical skills, and patterns of financing, along with litigation involving patients' desires, have aided in this service delivery change. Discrimination is still apparent; however, acceptance of the person who is mentally retarded is slowly growing along with public willingness to allow alternatives for their care and treatment. Professional and technical improvements and an attitudinal shift is making it possible for many persons to live and work outside an institutional setting. Previously, less than a decade ago, these people required

intensive personal nursing care and management inside institutions. Early detection and treatment, offer hope for non-institutionalization or community return for people who are mentally retarded.

Life for the individual who is mentally retarded is changing. Recently there have been a deluge of significant factors such as legislation, litigation, and proposed new standards that have affected the field of mental retardation. There is currently an emphasis on deinstitutionalization for the mentally disabled person and placement within the community, thus, decentralizing the residential facility and expanding the community-based alternative service model. Prior to these recent alternatives of care, the predominant pattern was to hide the person who was mentally retarded away in large medically-oriented institutions. The role of the nurse was that of a nurturing custodian and nursing intervention had little affect other than to maintain life. It is important to review past events and practices in order to impact the present and to advantageously plan future nursing roles and interventions in the field of mental retardation.

Historically, people who are mentally retarded have been perceived as deviant, subhuman, and/or an object of pity. These prevailing attitudes must be examined because

they are a part of our cultural heritage and not based in fact on reality. We must try to identify those influences that have perpetuated such attitudes within our society as it relates to those people who are mentally retarded. By understanding the past as it relates to mental retardation, we hopefully can avoid unnecessary repetition of errors and misjudgments in management of these individuals.

Changes finally may have occurred, not always dramatically but, litigation has sped up the process of recognizing and restoring to individuals who are mentally retarded their rights as citizens guaranteed by the Constitution. Existing services have been greatly improved and refined while new services are being developed and regulated to optimize services to all citizens. The field of mental retardation is advancing from the shadows of the dark ages of a decade ago into the light of the noonday sun. Nursing has the responsibility to make certain that the total person is considered when intervention is planned.

Purpose of the Study

History has repeatedly demonstrated the importance of past events in order to avoid repeating errors. In the case of mental retardation this is especially true. This

historical study will include events that are beyond the point of change. The variables that have influenced opinions and attitudes about mental retardation will also be examined. Through expansion of the knowledge base, through an understanding of the past, we can better discern future needs; especially related to the professional nursing role in the care of mentally retarded persons.

A need to record and remember events, whether knowingly or accidentally, gives rise to history. Recorded history is usually a description of those past developments and events which are either the works of man or which have affected man. The past can be known through memory, which is limited by one's own perception of what was witnessed, or it can be explored through the accounts of others. History may be preserved in written form or as physical evidence such as photos, buildings, or life styles. The task of the historical researcher is to collect accounts and evidence; then sift and weigh them in order to determine their meaning and validity. This historical study is presented in written form reflecting the sifting and weighing of that portion of history which reflects an era of tremendous change in the care and treatment of the mentally retarded persons.

Many individuals are affected by the decisions made by various state agencies and by professionals involved with the retarded citizen. The decisions made for these citizens have life-long effects on their care and treatment and their own self-perception. There will be many other individuals impacted by these agencies, professionals, and their decisions in the future. An understanding of the direction which the nursing profession is taking in this very dynamic area is needed. Nursing professionals will also need an understanding of the changes in the health care system and delivery of that care as it relates to citizens who are mentally retarded or also known as developmentally disabled, whether physically, mentally, or developmentally. Accordingly Bruininks, Thurlow, Thurman, and Fiorella (1980) identified that 75 years ago the predominant pattern was to place developmentally disabled people into large, isolated, medically oriented institutions. This pattern is in contrast to today's increasing emphasis upon normal life-styles and integration of people who are disabled as much as possible into community routines. Ida Axelrod stated at the first nursing program of the American Association of Mental Deficiency in 1965:

As more is learned about all these areas of prevention and treatment--the challenge to the nurse increases. Her closeness to the person needing care places her in a strategic position to help in seeking clues and applying answers. From her vantage point, she has the opportunity to make a major contribution to the many-faceted search for new knowledge in the field of mental retardation by search into the nature of nursing itself. (Grossman, 1973, p. 11)

Hunt (1961) observed that for numerous years it was commonly believed that one's intelligence was fixed by heredity. Society also believed that a child's rate of development was biologically predetermined. Such beliefs left little room for the role of treatment and less still for positive expectations of the mentally retarded person. These beliefs suggested that an infant's early learning environment should be designed to provide him an environment that properly matched his individual needs. In the 1960s the idea of early infant stimulation was a fresh water stream amidst the ocean of ignorance, control, and denial of rights.

This study was stimulated by the many current changes being made and proposed in the field of mental retardation. Some of the pertinent questions are:

1. What specific changes have occurred in the field of mental retardation?
2. What is the reason for changing the system of management of the mentally retarded?

3. What benefits have changes in the care and treatment of such persons provided?
4. How significant are these recorded changes?
5. What has been the role of the professional nurse in the institutional and community setting managing individuals with mental retardation?
6. How will changes in the field of mental retardation affect the role of the nurse both within the institutions and in the community?
7. What lasting influences on nursing will result from these changes?
8. How have legislation, litigation, and agency standards changed the management of the mentally retarded client?
9. What was the early development of the field of mental retardation, in general and in Texas?
10. What labels were used to identify this group of citizens?
11. What treatment measures have these individuals received and by whom?
12. Who is the appropriate spokesperson for this group of U.S. citizens?

These are the questions this study will examine and attempt to address.

Definition of Terms

For the purpose of this study the following terms are defined.

1. Deinstitutionalization - a policy oriented toward the establishment of alternative programs for the retarded in the form of community living arrangements and programs.

2. Developmental disability - "a disability attributable to mental retardation, cerebral palsy, epilepsy, or another neurological condition of an individual which is closely related to mental retardation or to require similar treatment, and which originates in childhood, is likely to continue, and constitute a substantial handicap to the individual" (AAMP, 1983).

3. Factors - those variables affecting mental retardation such as legislation, litigation, economic, perceptions, opinions, attitudes, etc.

4. Human management - "entry of individuals or agencies, acting in societally sanctioned capacities, into the functioning spheres of individuals, families, or larger social systems in order to maintain or change conditions with the intention of benefiting such individuals, their family or other social systems, or society in general (Wolfensberger, 1972, p. 2).

5. Institution - a 24 hour state-operated long-term care residential facility (Braddock, 1985).

6. Mental retardation - "refers to significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period" (Grossman, 1983, p. 1).

7. Normalization - affirming humanness to the mentally retarded person; allowing an existence as close to the normal as possible; making available patterns and conditions of everyday life as close to the norms of society as possible.

8. Role - "a cluster of related meanings and values that guide and direct an individual's behavior in a given social setting" (Riehl & Roy, 1980).

9. 'Total person' - "an open systems model involving two components--stress and reaction to it, an individual's total interface with the environment, a wholeness concept" (Newman, 1980).

This study has been undertaken in an attempt to answer some of the more prevailing issues surrounding the past, present, and future of the care and treatment of individuals who are mentally retarded.

CHAPTER II

REVIEW OF LITERATURE

This chapter provides a review of relevant literature dealing with the care and treatment of those individuals who are mentally retarded. The period of history that was discussed was the 25 year period of time in which the greatest amount of change occurred, 1960 to 1985. The role of the professional nurse involved in the field of mental retardation has evolved greatly during this time period. This study has draw upon the perceptions of nurses and people involved with the care and treatment of people who are mentally retarded at the community level. This portion of the study was accomplished by means of a collection of oral histories. An understanding of where the field of mental retardation was functioning at the community level may provide a basis for further research at the state level.

Initially resources were obtained and reviewed dealing solely with the historical aspects of mental retardation. Books identified the beginnings of the field of mental retardation, generally worldwide, then its inception in the United States, and more specifically its development

in the state of Texas. Kanner (1964) provided a comprehensive account of the early beginning of the field of mental retardation in Europe. Krishef (1983) and various commissions on the President's Committee on Mental Retardation presented the progression of this subject throughout U.S. history. The evolution of the field of mental retardation in Texas was studied using various state agencies, records, scrapbooks, and government documents.

A review of published sources revealed no specific research on the care and treatment of the mentally retarded. No historical data was available about the local state school in a single format. Some of the information provided was obtained from the scrapbooks kept by volunteer services at the local state school. The information was primarily composed of newspaper clippings and photos, and there were films available about state school life and the activities in which the residents could participate on campus. Additional information was obtained from policies and procedures, treatment plans, and management of the residential client through client records. A search of the local university library produced numerous books on the history of mental retardation. A book was found printed originally in 1958 by a nurse, Thomas French, and a physiologist, John Gibson, titled Nursing the Mentally

Retarded. The book originated and was published in London and has been released twice since 1958, the last edition in 1977. French and Gibson (1977) wrote statements in their book as: "The mentally retarded are people--children and adults--who do not develop normally.", "...they are not the equal of normal people of their own age.", "...because they develop slowly, imperfectly, and unevenly they require special care.", "Mental Retardation is a part of the branch of medicine called psychiatry.", "...the mentally retarded have never been normal.", "People suffering from mental retardation as a class of people maybe called:

mentally subnormal	defective
mentally handicapped	backward"

The book continues to define terms and levels of mental retardation. The assessment of the mental retarded person is also discussed. The role of the community nurse was identified as advising parents on "habit training, behavior difficulties, and the management of special problems such as epilepsy.", "...liaison between parents and hospital, and is often in a position to advise when admission is becoming necessary." The subliminal suggestions throughout this book reflect attitudes in the 1950s about individuals who are mentally retarded. No definitive role intervention

is identified for nurses who came in contact with parents of such children. The role, when rarely mentioned, was as an advisor or monitor, not an active manager.

A more recent book by Chinn (1979) dealt with the person at different levels of development and interventions appropriate for nurses involved with the care and treatment of people with mental retardation and that a multidisciplinary and interdisciplinary approach must be generated. Blackwell (1979) identified the role of the nurse as providing information and education to families and others in the general public about the handicapped. She also stated that nurses must be active members in related organizations that affect professional and public policies dealing with mental retardation. Blackwell (1979) believes nurses are respected professionals in the community and are in a position to act as an advocate for the child, family, or any aspect of the community dealing with the concerns of mental retardation.

An occasional paragraph or section was found in community nursing books or psychology books dealing with mental retardation. Pertinent articles in professional journals authored by nurses were collected and reviewed and dealt with the nursing aspects in the field of mental retardation. The nurse's role was cumulatively viewed

as a health monitor, counselor, educator and as a referral source to other community agencies. The identified role was primarily to aid the family and not the affected individual.

Articles in the early years, 1950-1960, identified the role of the nurse as an observer. The community nurse's role was that of case finding so that eventual placement could be initiated as the children reached puberty in order to prevent possible reproduction. Society was still deeply ingrained in the belief instigated decades earlier during the eugenics scare. The belief was that mental retardation was repeated in subsequent generations, thereby weakening the entire existence of humans, and allowing evil influences to permeate habitual civilization.

An editorial, unknown author, in Nursing Outlook (1957) addressed itself to mental retardation as a neglected subject. Mental retardation was mentioned as being overlooked by nurses allowing families to struggle with the heartaches, doubts, and even guilt for having such a child. Due to society's lack of interest, it was difficult to find articles ready to publish on nursing concerns dealing with individuals who were mental retarded. The Nursing Outlook (1957) article also addressed itself to defining mental retardation and various factors

affecting it. It also pointed out that lumping all handicapping conditions under the label of retarded was unfair and even disastrous. Social opinions and acceptance was effected by this lack of acceptance and understanding. This same article that called for increased interest states, "...nursing has shown the kind of interest in the tarde which, we believe, can be most helpful to parents" (Nursing Outlook, 1957). This derogatory labeling again reflected the subtle negative attitude of the 1950s.

Richard Allen (1968) summarized the historical record as:

About half a century ago it was pretty widely believed that every mentally impaired person was a likely delinquent, and that most criminal offenders were such because of impaired intellect. (1968, p. 22)

Articles in lay journals, basically provided referral sources for parents and families. They provided guidelines to aid the family in determining if their child was having problems and the possible causes for these problems. Several articles (Time and U.S. World) were written by parents recounting the difficulty they had in obtaining an accurate diagnosis, and the problems finding sources to aid them in managing their child properly. They stated that the majority of the professional's attitudes towards their children were clinical. It was only after the

Visiting Nurse Association entered the scene that life for the family and the child improved dramatically. Articles and editorials were reviewed describing various state programs involving the Public Health Nurse in professional nursing journals. Identification of the need for more nurses interested in this area was a repeated topic.

Shaw and Heyman (1982) published their findings from a longitudinal study conducted in England. They focused on nurses working in a "mental subnormality hospital". They explored the effects on nursing during a transition from a predominantly nurturant/custodial role to an educational/community oriented role. The researchers found that job satisfaction and self-esteem improved and that this related to a more positive evaluation of residents.

Articles reviewed on the trend of managing the mentally retarded client in the community were primarily published in professional journals. Gollay, Freedman, Wyngaarden, Kurtz, (1978) discussed the ways in which those referred to as mentally retarded were steadily progressing toward meaningful societal participation. He states that individuals who use the label "retarded" still reflect a prejudicial perception and resistance to community

placement. Gollay et al (1978), also noted the glaring lack of supportive community services for people who were mentally retarded, particularly in employment for adults. East (1983) believed that the community setting must resemble a normal home if the client was to succeed and if they were to truly integrate into the community. Bailey (1983) demanded attention to the fact that integration of the mentally retarded person into the community had developed new nursing problems and challenges that had to be faced. He identified that any movement from institutional nursing models of care to community health care delivery would mobilize nurses to carry out a self-reflection and soul-searching of the benefits if people who were mentally retarded were to be successful in the transition to the community. Nurses must view the resident or client as an individual and assume the responsibility to train other staff directly working with clients and to provide input into planning for client services. Savage (1984) discussed the practical issues involved in planning community accommodations in small group homes. A need for balance and flexibility from staff is needed if small group homes are to succeed. Price (1984) presented the pros and cons concerning segregated institutional care and integrated community living. One

side of the argument presented the fact that large institutions could best provide the specialized care for people who were retarded, while the other reflected large institutions as not homey or easily accessible to the community. Articles reviewed continued to reflect both sides of this debate with rational to supporting their positions. Articles published from the 1950s to the 1980s focused on the new role of the public health nurse in case finding of affected individuals.

A poignant article by two nurses, (Davis and Mahon, 1984), addressed the vulnerability of the individual who is mentally retarded. These individuals were denied their right to informed consent in various research studies. The article examined the dichotomous value system in which individual rights were overridden in a compelling need to protect society, (the state). The researchers, Davis and Mahon, believed that research about the mentally retarded has been undertaken to decrease burdens and increase benefits to society as a whole.

Burton Blatt, an eminent educator, has written four books that were reviewed for this study. Blatt has done much to open the eyes of legislators and increase public awareness of the care and treatment people who are mentally

retarded received. Blatt, according to Halpen, Close, and Nelson (1986), had the:

vision, spirit, and caring nature that inspired a whole generation of professionals in the field of mental retardation to seek more humane and normative ways to serve people with disabilities and who fueled a movement away from the formidable doors of institutions toward real homes in the community. (p. xiii)

Blatt's first book, Christmas in Purgatory, was published in August 1966, in hopes of inspiring lawmakers to initiate reform against the current levels of care the residents in institutions were receiving. His book attempted to strike a cord of awareness and to shatter the barrier of complacency raised in ignorance that surrounded the problem. Blatt's book was essentially a pictorial essay revealing the shocking reality of the treatment afforded to those individuals who are mentally retarded.

Lippman (1972) reported on a visit N.E. Banks-Mikkelsen, an internationally renowned authority in the field of mental retardation, made to California in November 1967 to see the best and worst institutions officials had to show. Reportedly he came away sickened at the treatment afforded by the richest state in the richest country in the world toward its citizens who were mental retarded. Bank-Mikkelsen stated in an interview, "In our country we would not be

allowed to treat cattle like that." "Perhaps you cannot treat cattle this way in your country either--cattle, after all, are useful, while the retarded are not" (p. 64).

Government officials rationalized: "The retarded don't know any better,"; "They don't really care how they are treated,"; "We are doing the best we can with the limited funds at our disposal,"; "Some of the retarded, after all, have only the intelligence of household pets" (p. 64).

Burton Blatt's second book reviewed was Exodus From Pandemonium, published in 1970. The book contained three individual books within it's context. The first was Blatt's recollections of what he had seen in the institutions and how these experiences affected him. He recalled the first time he visited a state school and how impressed he was with the beautifully manicured grounds. He described a distressing conference he attended with 100 fellow students, where patients were presented. The patients were made to stand and exhibit themselves to the audience while they were poked, moved, turned, and the presenting physician detailed their past and present histories including all personal information. In this book Blatt recounted the difficulties he had in publishing his first book, the opposition encountered, the rejection of publishers because it was too disheartening and

controversial to expose mainstream America to it. Finally published by a parent association for retarded children, Blatt described the overwhelming response his book produced. Blatt reflected on specific events that helped to turn the tide toward the human spirit and man's desire to live among men. He recounted a mother visiting her son regularly after he began wearing clothes, eating at the table, and "looking" like a human being. The mother said, "After all these years, I now have a son". "I lost my child many years ago and you have helped me find him" (p. 140). The second book was a collection of prose and poetry creating an illusion of Blatt's innermost feelings about his experiences in the field of mental retardation. The third book dealt with Blatt's estimation of the needs and values placed upon the care of people who were mentally retarded. He presented the statistical figures concerned with the incidence of mental retardation, its various forms, settings and expenditures of care. Blatt correlated the similarity in attitudes against people who were mentally retarded in state institutions and toward people imprisoned in Nazi concentration camps. He postulated that western culture has had a tendency to live lives from a perspective that permits society to tolerate evil and to segregate dependent

and deviant people, keeping the public from seeing, acknowledging, or tolerating them.

Souls in Extremis, Blatt's book published in 1973, clarified the problem of legally sanctioned human abuse which was not limited to those individuals incarcerated in institutions, but to their caretakers as well. Blatt described most institutions as hellholes and those few exceptions were like well-run animal farms: clean, routine, dull, patronizing, and indulgent in the self-fulfilling prophecy that children need what they get. He believed that misunderstanding of the basic conceptions of mental retardation and how to deal with it on an individual, familial, and community level guaranteed the production and continuance of human misery. His book was a compilation of data, observations, and experiences. Blatt cited the need for complete reexamination of humane alternatives for the care of people who are mentally retarded.

The final book reviewed was Blatt's novel, Revolt of the Idiots: a Story, published in 1976. Blatt admitted the book was fictitious, but did depict the reality of institutional life and the actual issues our nation faces. Throughout the book he exposed the truth as he understood it, believing that truth was stranger than fiction. The patient's perspective was the focus of the book. Adam

Mack was misdiagnosed as mentally retarded and in realization of this mistake he decided to plan and execute an escape of all the inmates from the institution. "He saw terrible things, heard horrible voices, stood as witness to the mocking and degradation...deceit, cruelty, and inhumanity" (p. 252). Blatt illustrated events that actually occurred and the eventual outcome he believed should some day come to pass. "Mankind must change if we are to reduce inhumanity, if humanity is to survive" (Blatt, 1970).

David and Sheila Rothman (1984) chose to report conditions at one particular institution, Willowbrook. There was desperate overcrowding, beds jammed one next to the other in the wards and hallways and the filth ubiquitous, and so virulent that intestinal diseases spread through the population. Staffing was one attendant to 50 or 60 inmates, injuries were frequent, residents self-abusive or assaultive to others. Willowbrook was the true story about an institution's scandalous treatment of 5,400 residents that were mentally retarded in the State of New York. Geraldo Rivera, a journalist and his camera crew penetrated the institution revealing, as he said, images seen in Nazi concentration camps, "vacant, bulging eyes, emaciated faces, giant heads with wasted bodies, naked children crouching in the corners, spindly-twisted

limbs, and they were just children" (p. 17). "The Pandora's box of our state school system for the retarded had been opened". "Our citizens have had a true glimpse of the misery, loneliness, and stench that have existed within for so many years" (p. 46).

Review of the literature revealed articles covering the subject of institutions and what litigation has done to refocus services for the mentally retarded citizen. Griffith (1985) felt it was the responsibility of the professional to decide who was best served by institutionalization and who would function best in the community. Professionals were charged with the programs and services each individual would receive. They had a major say in the decision of who got what and where. The article cited that the rights of the mentally retarded citizen have been clarified in the courts as inalienable although more minimal than the general public.

Initial movements to change the care and treatment of clients in institutions were reviewed in various articles published in the 1960s. The articles were an attempt to identify the problems and situations prior to the movement and report the new programs implemented, success of transition and attitudes toward the clients.

Teague (1966) cited research studies designed to find ways of promoting the concepts of training, education and habilitation in the institutional setting. Most nurses in institutions for individuals who were retarded had been involved in administrative and supervisory functions. They have been concerned only with the organizational aspects of the institution, Teague (1966) stated. She reported on a recent movement to involve nurses more in the direct care of the children and adults assisting them in tasks of daily living. The article cited that a movement was afoot to increase staff knowledge of normal growth and development in order to help residents of the institution realize their highest potential. The dilemma of institutional closure was addressed, including benefit versus cost and individual rights versus state responsibility.

The institutional setting had been seen as a final step in the care of persons with mental retardation. With the advent of alternative living arrangements, a major change in the role of the institution has occurred. Kini and Scabill (1975) believed institutions were only one alternative on the care continuum. The institution may be utilized at different periods in a person's life to assist him and his family with the various complexities that arise due to mental retardation. Institutions serve

as training centers for staff, professionals and clients. The institution may serve as an interim care facility while more suitable placement is sought. The institution, according to Kini and Scahill (1975) can provide the families with respite care and provide the client with temporary short-term training programs in self-help skills or behavior management.

Braddock and Heller (1985) reported two studies, one concerned institutional closure and the second concerned the implications of those closures. In the past decade institutional populations have dropped from 17,700 to 9,200. In 1982 there were 24 institutions scheduled to close and by 1985, 17 of those scheduled had closed. None of these institutions were in Texas. Three stated themes about closures were (a) it is hard to terminate government organization, (b) termination is accompanied by a budgetary crisis and ideological struggle, and (c) there is a lack of knowledge about systematic evaluation studies on the nature and consequences of program termination. Braddock and Heller's (1985) second study discussed the impact on clients, families, and employees with the closure of institutions. The study showed that all parties involved suffered dramatic effects and extreme stress. The clients experienced stress reactions with physical behavioral

symptoms. Families resisted these closures because they believed that the large institutions provided better care, more experienced staff, and greater security. The employers had decreased morale, performance, and a withdrawal from attachments with residents and other co-workers. The employers also showed an increase in physical and mental health problems. Braddock and Heller suggested guidelines to ease the stress reaction experienced by all people involved. Institutional closure is emerging as a national trend in the field of mental retardation. Studies about closure will need to be done in order to truly understand the total impact at the institutional level as well as at the community level.

Service Delivery Models

Service delivery models, specifically community services and deinstitutionalization, have helped guide the thrust of mental retardation services with the varied implications for management and care of those persons with mental retardation in the community.

There were a variety of care models related to service delivery for people who were mentally retarded. Baldwin (1985) compared and contrasted five models that have been applied to the field of mental retardation. The medical model

relating to diseases and illnesses has been applied to deviations from social norms relating to mental health. Inability to differentiate between mental handicap and mental illness has resulted in confusion regarding the origins and implications of mental retardation. Heiny (1978) has also noted that frequent interchangeability of the terms "retardation", "disability", and "handicap" was erroneous and would be ultimately only detrimental to recipients of the services. Inability to adopt well-defined terminology in favor of a more positive value-laden term inevitably distorted the values and beliefs attributed to persons who were mentally retarded. The developmental model, according to Baldwin (1985), was rigid in its adherence to programs of educational objectives and use of inflexible criteria. This model fostered simplistic conceptualizations of individuals who were mentally retarded. Behavioral models were the dominant force of delivery used with the populations that were mentally retarded. A belief of this model was the postulation that "abnormal" or "deviant" behavior may be changed using the systematic application of reinforcement procedures. The model reflected ethical and moral issues, the "images of man" was being implicated stated Bandura (1974). The Psycho-Educational Model was based upon an assessment of skills, deficits leading and

goals or target setting followed by a course of programmed instructions. This approach was a total rejection of clinical treatment components associated with the medical model and replaced with teaching components. Social-Ecological Models takes into account the person's habits, models of life, and relations to their surroundings. This allowed a broader analysis of conflicts and disharmony between the individual and their environment system. The normalization principle was representative of this orientation. This model focused on the immediate needs of people and attached equal importance to the individual and to the social ecology. The model has been an easy tool for political and power plays by misusing and manipulating. Care models providing a total delivery system of services continue to be chosen along socio-economic and political factors, based upon society's relative perceived status of persons who are mentally retarded. Professional understanding of the right of self-determination and least restrictive environment will hopefully reduce human error and ensure orderly, consistent, ethical approaches to benefit each citizen individually.

Theoretical Framework

The theory that provided structure and guidance to this historical study was primarily the normalization

principle. The concept normalization meant making available to people with mental retardation the conditions and patterns of everyday life that were available to all other citizens. The theory proposed that these people, regardless of the degree of retardation, were capable of physical, intellectual, emotional, and social growth. It also said that people who were retarded were more normal than they were abnormal. When these people, according to Gorman (1984), were placed in more normal settings with normal types of experiences and influences, they tended to develop more normally; and conversely, if they were placed in a abnormal setting with abnormal experiences they tended to develop abnormally. The theory of normalization was formulated by N.E. Bank-Mikkelsen (1969), and refined by Bengt Nirje (1969). Wolf Wolfensberger (1972) tried to convert the normalization principle into a scientific theory that was comprehensive, economical, and in harmony with social behavioral science. N.E. Bank-Mikkelsen was head of the Danish Mental Retardation Service and was credited with the concept of normalization. Bengt Nirje was executive director of the Swedish Association for Retarded Children and was the first to originate the principle systematically and elaborate on it in the literature. Wolf Wolfensberger was a Ph.D in psychology and special education. He was credited with

implementation of the normalization principle and of citizen advocacy.

Wolfensberger (1980) stated that the concept of normalization has been misunderstood and misused, and that people have failed to take this concept seriously as a "tightly-built, intellectually demanding, and empirically well-anchored megatheory" of human services and relationships (p. 234). Wolfensberger (1980) proposed the more explicit concept of social role valorization based upon his belief that the greatest objective of normalization must be "the creation, support, and defense of 'valued social roles' for people who are at risk of social devaluation" (p. 234). Normalization is considered implicit in the policy of deinstitutionalization. Deinstitutionalization into residential services reflects the current objective of normalization.

Deinstitutionalization was a complex phenomenon, according to Bachrack (1981), involving a process of two elements: the escheival (shunning or avoidance) of traditional institutional setting for the care of people with mental retardation, and the concurrent expansion of community-based facilities and services for the care of these individuals. Deinstitutionalization is a process, a fact, and a philosophy. Bachrack (1981) identified the

process as a series of dynamic and continuous adjustments involving constant accommodation of all components of the service delivery system. The fact was that deinstitutionalization was really occurring as reflected in national statistics concerning the depopulation of large institutions; and the philosophy was that community-based care was preferable to institutional care for all clients, that communities assume responsibility and leadership willingly for those individuals who were mentally retarded, and that the functions performed by institutions could be performed equally well, if not better, by community-based facilities.

Another concept necessary for this study was the term human management. Nurses exhibit significant impact and direction on clients in their role as human managers. Human management should be implicit in inferring that the nurse, as a manager, must consider the total person when dealing with individuals. The nursing profession has an obligation to provide purposeful intervention, which assist individuals in attaining and maintaining a balance between man and his environment, natural or created. Human management philosophy focuses upon individuals whom society believed to be deviant; that is individuals who were significantly different in some aspect from the "norm", when this difference was considered

to be of relative importance then the person was negatively valued by society at large. One of the major concerns of the normalization principle was the attainment and/or maintenance of nondeviant, or normative behavior.

When an individual was considered different or deviant, he was placed in situations where expected deviant outcomes were shared equally by the perceiver and perceived person. It became a self-fulfilling prophecy when these deviant individuals played out this role as it was defined by society. The expected deviant behaviors then became a person's natural mode of behaving, rather than a reaction to specific environments and situations. Historically, in the literature the primary perception of society towards people who were mentally retarded reflected actual prejudice which borne little relationship to reality. Objective verification was not and has never been an essential factor when shaping social judgments and policies. Wolfensberger (1983) stated people were considered to be of low value when their role in society was not perceived as valuable; consequently, a devalued identity was synonymous with deviancy.

Historians and sociologists have long recognized that deviant subgroups, (including mental retarded, visually handicapped, speech impaired persons, etc.) within a culture may be perceived as not fully human. This labeling as

subhuman might have been unconscious or conscious.

Literature dealing with retardation freely flowed with derogatory labels using animal and vegetable allusions and allegations. These subhuman perceptions were obviously implications for the needs for human control and domination. Historically, the literature revealed society has believed in the need for extraordinary control, restrictions, and supervision; thereby denying all privileges and rights as a citizen to these "deviant" individuals. Fortunately, today these beliefs and actions are illegal and unconstitutional. Attitudinally society as a whole and individually must realize that continued devaluation of human beings or dehumanization of the person with mental retardation is an unacceptable impulse that must evolve into a more humanitarian vain.

In order to recognize the symbolic ways dehumanization unconsciously manifests itself, one must understand the dynamics of this problem. Human emotions (disappointment, frustration, hostility, pity, etc.) play a principal role in the motivations for any controlling, belittling attitude used in the treatment and care of the individual with mental retardation. Some attitudes have been founded upon myths that retardation is the result of sins, wrongdoings, or a violation of the natural laws. Thus these deviants were

something to be ashamed of, hidden away, or put away. Presently there are alternatives such as prevention or reversal by means of education, training, and treatment. Prevention and reversal of institutionalization and prejudicial attitudes reflective of individuals who are mentally retarded as deviants are the main components of normalization. The theory of normalization was based on "letting the mentally retarded obtain an existence as close to the normal as possible" (Bank-Mikkelsen, 1969; Wolfensberger, 1972, p. 27). Nirje (1969) elaborated on this principle by stressing the need for "making available to the mentally retarded (person) patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society" (p. 27).

Nirje (1969) further explained the principle as:

1. Normalization means a normal rhythm of the day for the retarded.
2. Normalization implies a normal routine of life, i.e. not always structured.
3. Normalization means to experience the normal rhythms of the year with holidays and family days of personal significance.
4. Normalization means an opportunity to undergo normal developmental experiences of the life cycle, i.e.

experiences and opportunities should be consistent with the appropriate life cycle whenever possible; adjustments and special provisions should be made for the mentally retarded adult and elderly.

5. Normalization means that the choices, wishes, and desires of the mentally retarded themselves have to be taken into consideration as frequently as possible and respected.

6. Normalization means living in a bisexual world.

7. Normalization means normal economic standards for the mental retarded.

8. Normalization means that the standards of the physical facility should be the same as those regularly applied in society to the same kind of facilities for ordinary citizens (p. 74).

Consideration in the future with regard to the normalization principle is that deviance is in the eye of the beholder. Society has misinterpreted that normalization measures can be considered for some individuals and yet imposed on others in certain circumstances. "Decisions made to date have been based strictly on monies without consideration given to persons involved" (Developmental Disabilities Planning Office, 1979, p. 1). It is important to elicit and establish normative behavior that is culturally specific to the ethnic origins of people who are mentally

retarded. If normalization is to be fully implemented human management methods must allow for specifics of each individual's culture to be expressed. Cultural characteristics and behaviors may be interpreted as deviant by many who are outside that culture. The value of each human must surpass any construct or principle. Human management must be interlaced strongly with these values in future attempts to practice normalization principles. A person is considered deviant when he is seen as having low value in this role perceived by society. There are three consequences, according to Wolfensberger (1983), when people are seen as deviant or devalued:

1. Devalued people will be badly treated, rejected, persecuted, and treated in ways that will diminish their dignity, adjustments, growth, competence, health, wealth, lifespan, etc.

2. The bad treatment accorded to devalued persons will take on forms that largely express the devalued societal role in which they are perceived.

3. How a person is perceived and treated by others will in turn strongly determine how that person subsequently behaves (p. 235).

These consequences may be relieved by reducing or preventing this perceived difference and changing societal

perceptions and values of the devalued person. Future goals must be "the enhancement of people's social image" or perceived value in the eyes of others and the enhancement of their "competences" (Wolfensberger, 1980, p. 236). The reality is that, historically, social devaluation of individuals perceived as deviant is deeply ingrained in human mentality and attitudes. The most essential, initial need for society is to acknowledge and eliminate these impulsive inclinations to judge anyone who is different. "Attitude follows action. Attitudes must be appropriately portrayed by professionals if societal attitudes are to change" (Wielson, 1986). As health care professionals, patient advocates, and human managers this need is even more prevalent. Professional nurses must be initiators for change and motivators for elimination of prejudicial attitudes. Initially though, professional nurses must strive for sensitivity when making decisions about fellow humans, and above all, be knowledgeable of past events in order to make informed decisions about the future.

Goldberg (1972) revealed that the Scandinavian countries were advanced in the care, education, and rehabilitation of citizens who were mentally retarded. An unsuccessful attempt was made to integrate their system into the United States. The field of mental retardation,

despite all efforts, did not change dramatically; instead the trappings changed, leaving the heart of the program static. What was not transplanted from the Scandinavian program, according to Lippman (1972), was concern for individual dignity, attractive physical surroundings and a greater respect for the individual. The Scandinavian countries accept the responsibility for all its citizens. Americans petition the courts to prevent the opening of workshops or residential community-based centers. Government officials provided inadequate public appropriations, institutions had wretched staff-resident ratios, and Lippman (1972) believed discrimination and mistreatment continued even though society had the power to change these conditions. Lippman (1972) cited Gallagher's Law: "Money is always available for programs that society values" (p. 96). Lippman also noted that when funds are short, an attitude of the greatest good for the greatest number usually means nothing for the mentally retarded or handicapped person. Attitudes and reality were intertwined, Goldberg (1972) contended then that attitudes must change first if any real changes were to occur in the field of mental retardation. A conceptual model of the affects on individuals who are mentally retarded based on societal attitudes and perceptions is proposed by this researcher

(See fig. 1). Awareness of attitudes and perceptions of individuals who differ from ourselves is needed. Wright (1985) stated our language had a strong influence on our thinking and on our behavior. She also stated that it was widely acknowledged that correcting our language helped to correct our way of thinking and attitudes. Nursing intervention should be purposeful and aim for the client's highest potential. Nursing cannot impose prejudicial or judgmental attitudes upon persons who are mentally retarded. This historical study research proposes to benefit the mentally retarded individual by reviewing specific economic, attitudinal, and management factors, that have affected them directly. When the reader realizes actual treatment methods and questionable decision-making policies that existed; hopefully, repetition of past mistakes and misjudgments will be avoided and thus reducing client vulnerability.

CONCEPTS RELEVANT TO NORMALIZATION

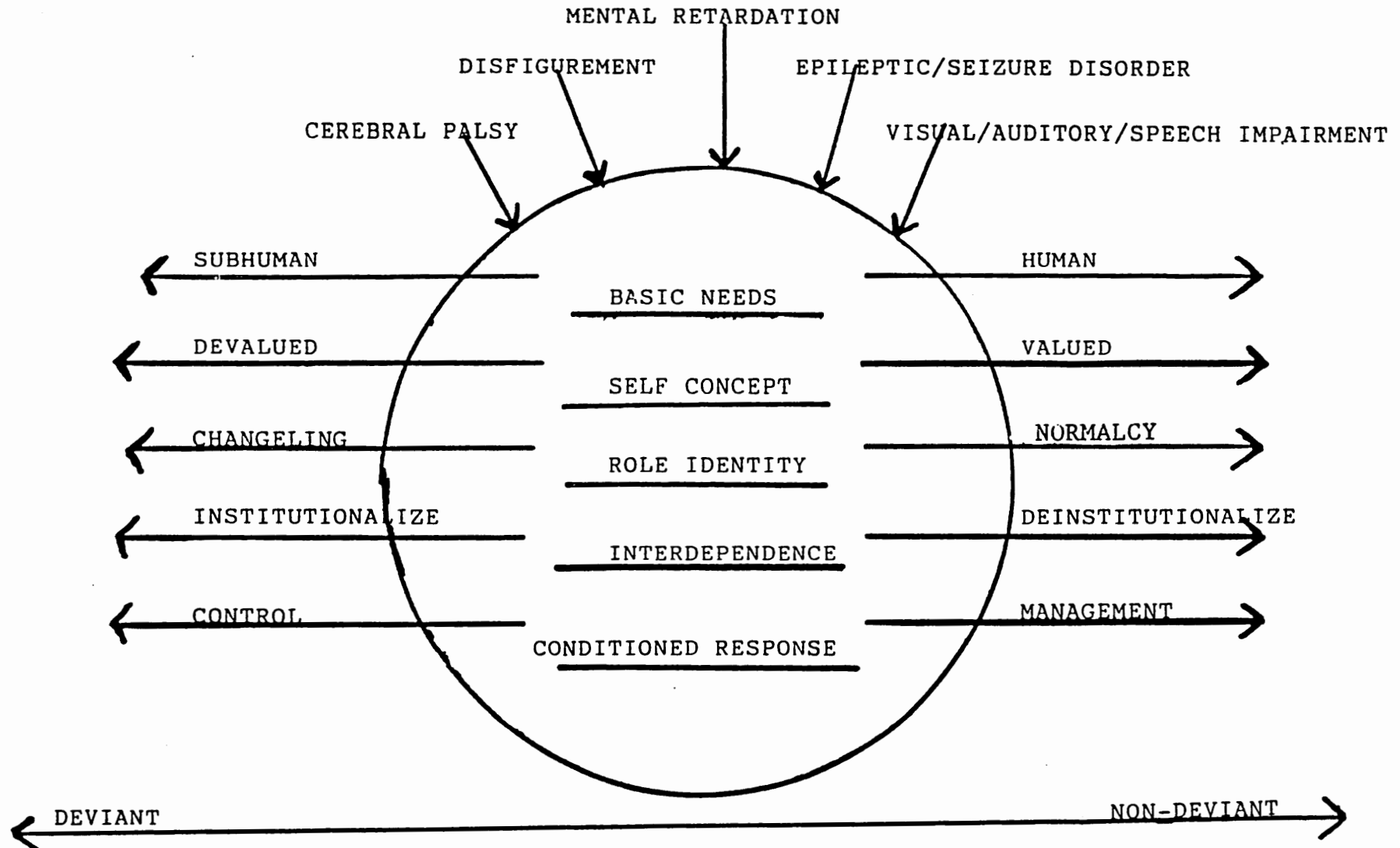


Figure 1: This conceptual model represents the basic components common to all mankind.

Faith

Knowing is believing
But belief is not insurance that one knows
And to be certain you do not know
While persisting in belief
Is faith.

Faith may not be knowledge
But it is strength
It may not be skill
But it is method
It may not have substance
But it is power.

Faith is not everything
But there is hardly anything without it.

There is more to a man than his faith
But little to sustain him except for it.

And everything to work for because of it.

Faith is not the total of a man's needs
But it permits him to continue.

In the absence of other things, faith will suffice.

Nothing else alone is enough.

Burton Blatt

CHAPTER III

METHODOLOGY

Data were obtained for this historical research study from several primary sources. A review of the literature was essential in order to provide the historical perspectives, philosophies, and evolution of mental retardation. Current events, legislation, and litigation were also reviewed in both government and public accounts demonstrated in written and verbal formats. Official audit tools, standards, policies, and objectives were examined. Privately produced publications were also included. Newspaper accounts of actual events reporting differing perspectives were also utilized.

Data Sources

Articles in professional journals concerning mental retardation published between 1950 to 1985 were reviewed. There have been so many changes in the field of mental retardation that it was necessary to understand what professional nursing attitudes and roles were and the progression of both variables. Lay articles were reviewed to enlighten and inform the reader as to what non-provider

opinions and beliefs were about mental retardation. These sources were used to examine the prevailing attitudes and management trends in the treatment of the mentally retarded individual. Information from various departments at the state school were reviewed. Volunteer Services maintains scrapbooks, films, and historical information about events and activities at the state school. Staff Development has ongoing updated information about the philosophy, objectives, goals, policies, and procedures provided to all staff employed at the state school.

Master charts containing nursing notes dating from the first clients enrolled at the state school, to the currently enrolled clients were used. These nursing notes provided a window to the past; i.e. attitudes, treatments, and the effectiveness of nursing intervention. A comparison of the notes written years ago with those written today reflected changing attitudes towards the mentally disabled. A nursing audit of a random sample of 25 charts covering the years 1960 to 1985, respectively, was carried out.

Oral histories recorded reflections of experiences and memories of events about the conception, evolution, and management of the state school and those residing within the school. Oral histories included interviews with nurses and other staff members who worked and are

currently working at the state school. The comparison of perceived roles was analyzed for past attitudes and management practices compared to today's goals and objectives. The oral histories collected from local nurses about their perceived roles before and after changes would be significant if they parallel the Shaw and Heyman findings (1982). Opinions about the way things were and about how involvement in the field of mental retardation has changed were solicited. Interviews with parents of clients that lived at the state school and are now in community placements provided insight into other dimensions such as education and care. Parent opinions about preceived changes provided an often overlooked perspective on the benefit versus cost, state responsibility versus private responsibility, and issues.

The collection of interviews and information from various sources was analyzed and a summary report included. Governmental regulations, standards, funding, and objectives were reviewed as to their relevance in the evolution of the treatment of mentally retarded persons. Professional and lay data were included to reflect major ideas. Finally pertinent oral histories were taken in order to obtain actual personal opinions about the management of the mentally retarded and perceived improvements. Individual

accounts of personal experiences and attitudes about the management of the mentally retarded were collected in order to identify past perceptions. Data collection from various sources were obtained as a foundation for understanding why nursing roles were often and primarily viewed as 'custodial'. A view of nursing roles in 1960 as compared to nursing roles in 1985 emphasized the vast changes within professional nursing and the overall evolution of these roles in the field of mental retardation.

Organization of the paper is structured in such a manner so as to allow the reader to be a part of the progression of events. Following an introduction to the study, a general review of historical data dealing with the field of mental retardation is detailed. A specific review of the historical aspects of the field of mental retardation as it developed in Texas is then discussed. Blocks of ten years present major occurrences specific for that decade dealing with selected variables in the field of mental retardation. Legislation, litigation, attitudes and the role of the nurse are considered and what effects these selected variables have had on the field of mental retardation. Oral histories were used to support both professionals articles written in each time span. Standards and regulations that now guide institutions and communities-

living alternatives were presented. A summary report of the chart review is included to reveal nursing intervention in the institutional setting and notations of progressive professionalism in dealing with persons who are mentally retarded. No statistical analysis was performed, nor did a single factor such as age, sex, or level of retardation bear any special consideration in this study. All statements are considered implicit when relating generally to any person who is classified as mentally retarded.

CHAPTER IV

ANALYSIS OF DATA

Introduction

By the end of 1940, parents had decided they had had enough of the familiar cliches they had heard for much too long: "Your child is defective, put him away and forget him...", "Your child is a vegetable--he will never be anything else...", "Your daughter must be sterilized if she stays in the community...", "There's no room in the institution; your son will be put on a waiting list...perhaps in two years there will be space." Parents were heart-sick, frustrated, and outraged at the apathy and attitude professionals in the field of mental retardation demonstrated. The solutions society afforded these parents were to hide their child away or to manage their problems themselves. Parents felt there must be a better way to provide care, treatment, and services for individuals who were mentally retarded than the ones they were being offered. Parents wanted to rid themselves of the guilt, doubt, and recrimination society was heaping upon them. Over all the world the parents of children who were mentally retarded ranked in the multiples of thousands, and pockets of hope began springing up with

one idea. That was to find improved services for the children.

Public opinion began shifting from one of rejection, indictment, despair, anger, closed doors, and closed attitudes. Parents began uniting to focus attention on the plight of their children. A new attitude toward children diagnosed as mentally retarded, defective, deformed, spastic, epileptic, or mishappened was evolving. Regardless of their condition they were still human beings. A movement began toward the belief that education was not only possible for children who were mentally retarded but was in fact their right. Education could provide these children with a realization of the worth of life, allowing them to learn, laugh, and live among the whole of mankind. New attitudes toward the mentally retarded as productive workers were emerging. When one is able to work, self-worth and self-esteem increase. Who deserved this opportunity more than those people who were mentally retarded.

Society, worldwide, has a deeply ingrained image of people who are mentally retarded. Their inherent cultural belief systems warned them that children who were mentally retarded were a product of heredity, that they were social degenerates, and the progenitors of evil. Society looked

at these individuals as sub-human or even non-human contaminants of the entire human race. This unrealistic attitude has persisted in mainstream American consciousness, in statutory codes, in regulation of the educational systems, in court proceedings, in the judgments of many professionals, and in the dehumanizing environments under which mass case institutions were allowed to function for so long. These false societal images were maintained over five decades, through the depression and through the wars of the 1930s and 1940s. Even through the enlightened era when sufficient knowledge was available to expose these fears and images as erroneous and unfounded, still these attitudes persisted.

The historical perspective now makes it possible to see the enormous injustices that this misunderstanding of mental disability perpetrated on those individuals who are mentally disabled and on their families. There are a variety of factors which influenced the development of these misconceptions, how the consequences eventuated, and why some still persist today.

The writings of Blatt, Davies, Deutsch, Haskell, Sloan, and Wolfensberger, among others have contributed to societal understanding of the ideology which existed to blame persons who are mentally retarded for all social

ills and manufactured the belief that society needed to be protected from them. One can trace the emergence of humanitarian efforts in the treatment of the persons with mental retardation back to the 1850s. Initially the efforts was to educate the "poor idiots" in order to make them more socially acceptable. Within 65 years, all those humanitarian efforts were transformed into programs designed to identify, segregate, and sterilize every feeble-minded person viewed as a menace to social decency and racial purity: to the end that they not reproduce their kind. This is language typical of many statutory provisions developed to control individuals who were mentally retarded well into the 1950s.

The industrial revolution, the exploitation of labor, the onslaught of immigration, overcrowding, and the civil war caused more frustration, and influencing policies and statutes relating to individuals with mental retardation. Worthiness became equivalent to work authority and property in industrial democratic societies.

Education was a middle class privilege, as industrial societies placed a high premium on intelligence. Intelligence was a measure of success, upward mobility, economic and social security, and at the top of the scale of human value. Limited intelligence was epitomized as

a complete inability to compete effectually for the good things of life and was therefore regarded as a stigmatic or degrading situation. Limited intelligence was the most dreaded of all disabilities: worse than crippled limbs, blindness, or deafness. Words were coined to identify individuals who were mentally retarded as "idiot", "imbecile", "moron", "unfortunate", and many others. It was believed that these individuals were to be pitied and helped. They were seen in some culture as monstrous purveyors of evil to be degraded, mutilated, and at remote times mercilessly destroyed.

The blind do not become "blind with rage,"
 The deaf do not "turn a deaf ear,"
 The mentally ill do not "behave unfeelingly,"
 And, the retarded do not "act stupidly."
 Those are the weaknesses of ordinary men--
 Who commit most of the world's extraordinary evil.
 (Burton Blatt, 1970, p. 152)

General History of Mental Retardation

Historical records of care and treatment of individuals who are mentally retarded are found in a few isolated passages from Greek and Roman literature, and from the Bible, the Talmud, and the Koran. Plato wrote "...the offspring of the inferior, or of the better when they chance to be deformed, will be put away in some mysterious, unknown place...". Mohammed's command to feed and home "those without reason" and give them kindly word is one

example denoting the existence of mental retardation. There is no evidence to indicate any specific or organized efforts to shelter, protect, or train people who were mental retarded in the remote past or antiquity. Ancient Romans and Spartans practiced elimination of severely defective individuals by abandoning them and exposing them to the elements. There are reports that some wealthy Romans would keep their children that were retarded at home to serve as entertainment for guests and help with the work. Those individuals who entertained were known as fools and jesters, some even gained great reputations. Gabba, the fool of Emperor Augustus, was one of these. The prevailing belief of the Romans then was to eliminate the weak from the society. The philosophy of that time emphasized physical and mental fitness for the "glory of the State".

A more humanitarian and charitable approach developed with the advent of Christianity. During this period attitudes changed and those people who were mentally retarded were considered with sympathy and compassion.

During the Middle Ages the first asylums were constructed to provide protection and safety to those in need. Christian churches offered the residents "protection under God". In certain parts of Europe persons

with mental retardation were allowed to roam freely about without any limitation because they were considered to be "the infants of a good God".

Phillip IV, ruler of Spain in 1621, gathered every available kind of handicapped and retarded individual he could find to his court for purposes of entertainment. Court jesters were given freedom of the royal court, those who were able to survive the abuse and disdain lived relatively well within the royal court.

During the Renaissance era the individuals' personality was thought sacred, and each individual was held responsible for their own actions. Those who could not be responsible faced a great deal of pressure and treatment that was cruel and harsh. This period of time gave birth in literature to derogatory terms like "Simple Simon", "village idiot", "fool", and "bumpkin" when referring to persons who were mentally retarded. This era also changed asylums to dungeons for punishment with keepers rather than providers. Sir Anthony Fitz-Herbert in 1534, attempted to define the term "idiot" in the terminology of the time, but it wouldn't be until 1690 that John Locke first distinguished between "idiots" and those who were "insane".

Religious warfare raged during the Reformation and those church hospitals caring for people who were mentally

retarded were closed. During this period a religious leader, named Martin Luther, regarded people who were mentally retarded as "merely a mass of flesh, a changling with no soul, possessed by the Devil". This attitude subjected them to extreme measures of exorcism and torture.

The field of medicine remained relatively unconcerned about the issues involving mental retardation. It was not until the latter part of the eighteenth century that the medical field became realistically involved in mental disabilities. Philosophers and theologians opposed any move to involve medicine, which was seen as an intruder. People who were mentally retarded were regarded as social outcasts and a blemish on society; therefore, a problem to be dealt with by the "experts". They were indiscriminately segregated along with common criminals and social misfits. These abuses were not considered maltreatment because it was commonly believed that the people who were mentally retarded had no knowledge of their environment.

In the first half of the nineteenth century an increasing interest in mental retardation began in France and Switzerland, spread to the rest of the civilized areas of Europe, and finally to the United States. One of the earliest attempts to educate the handicapped was done

by Jacob-Rodrigues Pereire and Abbe de L'Epee. Pereire and L'Epee developed an educational training program for the deaf. Pereire and L'Epee taught the deaf a form of sign language and invented a method to help them calculate. Although these men never worked directly with the people who were mentally retarded, they are credited with inspiring others to follow in their steps with attempts to stimulate the thought process of individuals with mental retardation.

Jean Itard made the first actual attempt to teach a severely retarded child. His attempts were focused on a boy who had been seen running wild and naked through the French woods. Itard believed that the boy's mental faculties had been arrested due to his environment and felt the boy's condition was curable. Itard worked with the "Wild Boy of Aveyron" for five years at which time, Victor was able to read and understand a few words, possessed limited speech, and limited sensory skills.

Itard's early work places the initial interest in educating people with mental retardation at the beginning of the 1800s. Itard's report, "Educating the Mind of Victor", depicts his conviction that the mind could be educated by a system of sensory training and habit training. Itard's work demonstrated what a highly structured,

educationally creative approach would accomplish when working with people who are mentally retarded.

Edouard Sequin, a French physician-educator, became interested in mental retardation. Sequin, who became associated with Itard, believed that emphasizing the sensory organs of those individuals who are mentally retarded could enhance their education. Sequin developed a systematic program of sensorimotor training, based upon the theory that when individuals with mental retardation were exposed to enough physiological stimuli, education would occur. In 1848, Sequin emigrated to the United States when he played a major role in the development of programs for children with mental retardation.

A Swiss physician, Johann Jacob Guggenbuhl, contemporary to Sequin, established an institutional setting in the Swiss Alps called Abendberg (in 1839) to provide education and medical treatment for the "cure and prophylaxis" of cretinism. Guggenbuhl was convinced that through habituation of regular routine, memory exercise, and speech training one could awaken the soul of the "feeble-minded children". Guggenbuhl's work was hailed worldwide as a major reform in the treatment and education of individuals who were mentally retarded. Guggenbuhl achieved success and fame throughout the civilized world as the initiator

of the colony plan for institutional care for people who are mentally retarded.

Christian Friedrich Nasse, a psychiatrist from Bonn, wrote to Guggenbuhl:

Since the start of your undertaking, I have followed your procedures with joyous consent...I am convinced that the aim of your beneficent institution will be achieved victoriously. It is highly meritorious to take the decisive first step for so large a group of unfortunates who have lived on hopelessly so long as not even the thought of the possibility of helping them has occurred to anyone. (Kanner, 1964, p. 25)

William Twining from England, after visiting Abendberg in 1842, (Kanner, 1964, p. 25) proclaimed that through human exertion the mind that was once considered a senseless mass, could be awakened and educated.

Institutions based on the Abendberg example opened in Germany, Austria, Great Britain, the Netherlands, the Scandinavian countries, the United States, and elsewhere staffed by people trained at Abendberg. Guggenbuhl traveled about lecturing and counseling, heralded as the man that brought new life for a neglected portion of mankind.

There was criticism from the beginning, as some felt that Guggenbuhl promised too much. Some critics resented Guggenbuhl's belief that Switzerland had been selected by Divine Providence to guide the way for other nations in fulfilling God's merciful miracle. They also resented

his belief that he had been the one chosen to perform those miracles.

Eventually people began to realize that these children could not be cured by Guggenbuhl's prescribed methods. By 1853 Guggenbuhl was viewed with animosity and frustration at failed promises. In April 1858, a British Minister, Gordon, visited Abendberg and found the children totally neglected and the entire institution in disgusted disorder. Guggenbuhl had spent little time at Abendberg due to his travels and the institution became deplorable and eventually was forced to close.

'We lock these unfortunate creatures in lunatic cells, as if they were criminals', exclaimed Reil in 1803, 'we keep them in chains in forlorn jails, near the roosts of owls in hidden recesses above the gates of towns, or in the damp cellars of reformatories where no sympathetic human being can ever bestow them a friendly glance, and we let them rot in their own filth. Their fetters scrape the flesh from their bones, and their wan, hollow faces search for the grave that their wailing and our ignominy conceals from them.' (Emil Kraepelin, in Blatt & Kaplan, 1974, p. 52)

Guggenbuhl died at the age of 47, alone, and feeling a failure. Guggenbuhl did make an impact on the field of mental retardation and he must be acknowledged as the indisputable originator of the care and treatment of individuals in institutions.

History of Mental Retardation in the United States

The almshouse method of treatment and care began to emerge in the United States around the 1800s. The philosophy of these facilities was to remove the destitute, sick, insane, and mentally retarded persons from society. Society did not care how these aimshouses fared nor whether any program for treatment was implemented. In 1841, Dorothea Dix, a New England school teacher, launched a significant effort to change society's attitude toward the care of the handicapped. She visited jails and almshouses in an attempt to have appropriate inmates placed in mental hospitals, and sought programs to provide decent care and attention. Dorothea Dix's approach was a brief sympathetic understanding which was soon to be replaced.

Samuel Howe, a neuropsychiatrist, led an investigation in 1846 to determine what could be done for individuals with mental retardation. In Massachusetts, Howe convinced his peers that it was a public responsibility to train and educate individuals who are mentally retarded. Howe, imitating a model of Abendberg, initiated institutional care in the United States. Treatment methods for individuals who were mentally retarded were introduced during the 19th and 20th centuries. The early efforts

of Itard, Sequin, and Guggenbuhl were used as models for development of Howe's own method.

Sequin migrated to the United States and worked as a consultant to Howe. Howe became the director of the first state supported school for individuals who were retarded, in South Boston, Massachusetts. Sequin served as consultant to other states as they organized institutional facilities.

In 1876 the American Association on Mental Deficiency was founded and Sequin became the first president. Sequin established a pattern of training schools for persons with mental retardation, drawing on Guggenbuhl's philosophy that the condition of mental retardation in these people could be cured and that institutional care would eventually help them to become normal. It ultimately became obvious that the individual with mental retardation could not be "cured". A shift occurred in American institutions to concentrate efforts on trying to help these individuals function at their best possible level. These first institutions began their work with people who were mentally retarded in a most positive fashion. This was shortly before the focus switched from helping and protecting the residents to protecting society by isolating and segregating any deviant individual.

Governor Butler of Massachusetts in 1883 addressed the legislature expressing popular misunderstanding of Darwinism by stating:

When the state shall have sufficiently educated every bright child...it will be time enough to undertake the education of the idiotic and feeble-minded. I submit that this attempt to reverse the irrevocable decree as to the survival of the fittest is not even kindness to the poor creatures who are at this school...none of the students have become self-supporting...a well cared for idiot is a happy creature. An idiot awakened to his condition is a miserable one.

Several scientific developments were popularized in distorted form to fulfill the image of the individual who was mentally retarded as a depraved menace to society. The Darwinian theory of survival of the fittest became interpreted as survival of the worthiest.

This shift occurred during the late 19th and early 20th centuries. A number of respected leaders in the field of mental retardation created some unreliable research reporting that mental retardation was a familial or hereditary condition. These research studies supported the idea that retarded parents produced intellectually retarded and socially deviant children. Professional and popular belief at the dawning of the 20th century was focused on the menace which it was felt that mental retardation presented.

Richard Dugdale's thesis was that retardation bred retardation, along with every conceivable social and

and physical ill. Dugdale's study was, The Jukes: A Study of Crime, Pauprism, Disease and Heredity, written in 1877. The next study was by Reverend Oscar McCulloch titled, A Study in Social Degradation, written in 1888. McCulloch believed his study proved the hereditary nature of mental retardation.

Gregor Mendel's study was rediscovered in 1900 and provided a new and potent weapon to persecute those who were intellectually deficient. Mendelian law lead to the belief that intelligence and lack of intelligence would breed as recessive and dominant characteristics.

In 1901, Galton in his misconception of Darwin's theory proposed that by eliminating the unfit, man could actively assist nature in promoting survival of the highest quality of human beings. Thus the "eugenic scare" or movement based on social Darwinism was lauched. In 1905, Simon and Binet's scientific work toward measuring intelligence through standardized school work as a measure of success or failure provided further evidence of the menace the mentally retarded posed, and the need to protect society from this weak link.

A 30-year leader in the field of mental deficiency, Fernald, reported in 1909 that women and girls who were mentally retarded were sources of unspeakable debauchery

and licentiousness, polluting the lives of youths in the community. In 1912, Fernald said that women who were retarded were immoral, carriers of venereal disease, and gave birth to children as defective as themselves. Myths developed that individuals with mental retardation had abnormally strong and utterly ungovernable sexual drives. This idea was the impetus for the establishment of rigid and absolute separation of the sexes at all institutions.

In 1912, Henry Goddard conducted several influential studies concluding that mental retardation was genetically transmitted and perpetuated in families due to "bad blood". Goddard proposed that half of all inmates in penal individuals were individuals who were mentally retarded, proving a correlation between mental retardation and criminality. A third study by Goddard suggested that special education training for those individuals who were mentally retarded was not helping to a significant degree "proving" that they were suffering irreversible hereditary factors that produced the condition of retardation.

Dugdate, McCulloch, and Goddard's findings provided overwhelming evidence against people with mental retardation. The influence of their work reversed all the positive approaches that had been established and conceived by Guggenbuhl, Itard, Sequin, and Howe. A quote by Barr,

a chief physician at the Pennsylvania Training School for Feeble-Minded Children in Elwyn, Pennsylvania in 1904, best reflects the popular sentiment of the time:

The transmission of imbecility is at once the most insidious and the most aggressive of degenerative forces; attacking alike the physical, mental, and moral nature, enfeebling the judgment and will, while exaggerating the sexual impulses and the perpetuation of an evil growth, a growth too often a parasitic, ready to unite with any neurosis it may encounter, and from its very sluggishness and inertia refusing to be shaken off; lying latent it may be, but sure to reappear through a century to the fourth and fifth generation. (p. 102)

The next landmark occurrence was the eugenics movement which concerned itself with factors which improve the quality of the human race. Sir Frances Galton published several articles describing intelligence and ways of evaluating and measuring intelligence. It was feared that if individuals with mental retardation were allowed to procreate, evil, crime, and disease would spread through the human race. Belief that the only way to curtail reproduction of people with mental retardation was to sterilize them and sexually segregate them for life. Within fifty years, nearly 30,000 people were sterilized in the United States under the sterilization laws most states adopted. Institutional populations soared while quality of care remained poor. Once again individuals who were mentally retarded became outcasts. They were

segregated, isolated from society, and sterilized without due process considerations.

Community services were sparse or totally non-existent due to the heavy focus on institutional care for those people found to be mentally retarded. Educational programs did exist as a means of identifying individuals who were mentally retarded for eventual and inevitable institutionalization.

The lack of data to support the falacious research was never even questioned. Professionals of the time lost their objectivity and shaped their findings to parallel contemporary attitudes. The impact of the distorted information perpetuated by the studies of Dugdale, McCulloch, and Goddard lasted for about ten years. Unfortunately, the distortion from that period colored the formulation of those institutional programs. Once these false findings were embeddled into the programs, philosophies, and attitudes of the institutional system, they did not change easily. Many institutions practiced oppressive, isolated and segregated programs from individuals who were mentally retarded; thereby effectively perpetuating deviant images and fears within society.

Stupid or mentally deficient patients (during the early nineteenth century) because they seemed passively to endure whatever was inflicted upon them, gave rise to the popular assumption that they were

insensitive to hunger, cold, and pain even though the opposite was proven by their obvious emaciation, by their frozen members, and by their dying from injuries. The result was that their suffering was looked upon as self-evident and unalterable while the significance of their plight was never fully appreciated.

Emil Kraepelin

(Blatt & Kaplan, 1974, p. 26)

A proposal for the care of the mentally retarded in 1912 was made by the State of New Jersey to extend the concept of controlling the lives of those with mental retardation. The proposal arranged for children under 12 years to be sent to special classes in public schools while having the parents bear the expense. Children 12 to 20 years would be committed to institutions and the expense born by the municipality and what the parents could contribute. Those 21 years and over were to be cared for by the state at its central custodial institutions with the parents contributing what they could. All "idiot" cases with unclean personal habits and special needs were to be sent to the state institution or almshouses.

Such plans to segregate mentally retarded people by massively isolating them from society was reflected in the growth of institutional populations from 1850 to 1975. During the earlier period of education promoted by Howe, Sequin, and Wilbur, growth had been slow even though facilities were often overcrowded. Wilbur estimated

a total of 1,282 residents in all institutions in 1874, a ratio of .03 per thousand of the U.S. population. By 1900 with the custodial character of institutional care, the number rose to 7,000, a ratio of .09 per thousand of the general population. Following the peak of the eugenic campaign in 1925 there were about 40,000, a ratio of .34 per thousand of U.S. population. During the time span between 1925 and 1950, the population of institutions grew at a greater rate, rising to 128,000 in 1950, a ratio of .83 per thousand population. Residential population finally peaked after 1950 to 190,000 in 1965 at a ratio of nearly one per thousand population. The movement to deinstitutionalize accompanied by the growth of community services had brought about a reduction for the first time since the institutional movement was initiated. In 1975 institutional populations were estimated to be between 165,000 and 170,000, a ratio of .78 per thousand population. One rationale for the increased number was the success that medical science had had at saving and prolonging life. The reduction in infant mortality and prenatal loss resulted in an increased survival of children diagnosed as mentally retarded. A possible second factor in increasing the institutional population was that the pattern of institutional care had become a well-established

and socially acceptable alternative care system. Substantial investments had been made in buildings and land, making it easier to enlarge and overcrowd the existing facilities than to develop new resources for community management. A third reason for institutional population increases was that the image of the demonic, fearsome defective was well ingrained into the American consciousness and would not be easily forgotten.

Knowledge had progressed beyond the era of the eugenic scare, but the cultural lag was a strong determiner of social behavior. The most important reason for continuation of discrimination toward people who were mentally retarded was a culmination of critical events. During the 1930s and 1940s the nation was in the grips of the Great Depression. There were no resources and no motivation left to consider the plight of people who were mentally retarded. There was no longer an interest in the programs and services or the lack of them, for people who were mentally retarded. Social strife created magnified hardship situations in the family with a mentally retarded child. Shortly after the depression World War II broke out, diverting all public resources toward providing basic social and economic security to the population at large and to the astronomical costs of global war. During these

years, doctors spoke of incurability and recommended placing children in institutions, psychologists measured I.Q. and gave little help, social workers knew little of the problems families faced when dealing with mental retardation, and professional nursing in the community setting did little more than identify and monitor children who were mentally retarded. In the institutional setting, they performed administrative, supervisory roles within a maintenance and custodial care system. Eventually, public pressure from the parent movement together with professional advancement drew attention to the abominable conditions of institutions. Reform was slowly generated and though often superficial, made it less painful to place one's child in an institutional setting. Parents had an overriding need to ensure the security of their handicapped child. Community resources not yet existent, leaving the institution the only available public resource for the child unable to be cared for at home. Parents pressure did cause some improvement in the quality of residential care in institutions. The parent movement also had an impact on initiation of new community services although they were slow to develop. A massive attack on the problem was necessary in order to bring about any significant changes. Richard Hungerford states: "The

wheels of humanitarianism never grind as fast as when they are aided by utilitarianism" (Blatt & Kaplan, 1974, p. 82).

White and Wolfensberger (1969) described three stages of development in the treatment of people who are mentally retarded from the middle ages through the 19th century to the early 20th century. From 1850 to 1880 there was an honest effort to make the deviant individual non-deviant. From 1870 to 1890 there was a desire to shelter the deviant individual from society. From 1880 to 1900 a dramatic change reflected societal anxiety and the desire to protect society from the deviant individual.

The mentally retarded continue to be the least of the last minority in the United States--the least understood, the more different, and the least appreciated. Still it seems probable that, in the words of Voltaire, 'Their time has come and, in spite of the ignorance and general indifference of the public, the lot of the retarded is looking upward'. (Richard Hungerford in Blatt & Kaplan, 1974, p. 78)

Some notable leaders and pioneers have arisen for humane residential care of people who are mentally retarded. Each has struck a blow for truth and reality. Each in their own way has tried to awaken the sleeping public.

Notable Leaders

1. Niels Bank-Mekkelsen
2. Gunnar Dybwad
3. Fred Finn
4. Erving Goffman
5. Karl Grunewald

6. Robert Kugel
7. Leonard Mayo
8. Bengt Nirje
9. Thomas Szasz
10. Jack Trizard
11. Wolf Wolfensberger
12. Burton Blatt

Pioneers

1. Albert Deutsch
 2. Dorothea L. Dix
 3. Jean-Etienne-Dominique Esquirol
 4. Johan Jakob Guggenbuhl
 5. Samuel Gridley Howe
 6. Emil Kraepelin
 7. Philippe Pinel
 8. Ernest Roselle
 9. Edouard Sequin
 10. Henry B. Welbur
- (Blatt, 1970, p. 152)

1930

A few changes occurred in society's attitudes towards people who were mentally retarded. The nation was consumed by a devastating depression while individuals were concerned primarily with their own survival. President Hoover called the White House Conference on Child Health and Protection in 1930. The conference was notable for its comprehensive concern for mentally and physically handicapped persons. A generic term was coined to refer to people who were mentally retarded. "Mental deficiency" was based on an I.Q. of 85 or less, and included an estimated 15% of the total population.

Concentrations of feebleminded children were found in homes for dependent children, county poor farms, and

in the homes of those at lower socio-economic levels. Persistent evidence found higher proportions of mentally deficient persons in penal and correctional institutions, but this was attributed to their social vulnerability and poor social environment. A report on social control and management was hopeful that a large proportion of mentally subnormal persons could become socially useful instead of a social liability. During the depression years institutions became so crowded that little training, education, or proper treatment actually occurred. Thousands of children who were mentally retarded or deficient were on waiting lists without any community services, social services, supervision, or proper care.

1940

The onslaught of World War II demanded the nations resources in order to survive, thus leaving none for consideration of the plight of the mentally retarded person. Following the war, government placed more emphasis on child welfare services and children of minority groups. Recognition that minority children were disadvantaged educationally and health-wise lit the efforts to correct this disadvantage. Children with special problems were cared for in the context of child welfare. Many children

with special needs were placed in institutions where it was believed they would receive care more suitable than the rehabilitative services they could receive from their community. Recommendations in the late 1940s were for early discovery and diagnosis, modified school curricula, sufficient availability of institutional care, and research on epidemiology, diagnosis, education, and treatment techniques.

1950

There were major advances in the treatment care of people with mental retardation in the decade 1950. Parent groups and others formed the National Association for Retarded Citizens (NARC). They pressed for improved services in both the community and in institutions. Their impact was tremendous; they became an organized advocacy group for improved programs and services.

The Fifth White House Conference on Children and Youth in 1950 identified mental retardation as one of the two major problems affecting children in the United States. The Los Angeles Children's Hospital was given a grant to establish a diagnostic clinic for children with mental retardation. The Bureau of Vocational Rehabilitation began active funding demonstration projects

to start sheltered workshops. By 1956 the Children's Bureau had 29 demonstration projects providing services to people who were mentally retarded in different areas of the United States. The Bureau also offered new ways of delivering services and training to professionals interested in the field of mental retardation.

Research from Skeels and others provided evidence that intellectual functioning changes as the experience and emotional state of the person changes. Intelligence tests were not all-encompassing or definitive as had been thought. New studies supported a view that no single cause for delinquency existed, nor was there a single factor like low intelligence, poverty, or a broken home. In 1950 there was a major shift from the belief that all these social ills of poverty, crime, and insanity were the responsibility of mentally deficient persons toward a belief that complex social miseries contributed to decreased intellectual capacity, delinquency, and mental illnesses.

1960

John F. Kennedy named a panel of eminent professionals to develop a national plan of action to deal with the problems of mental retardation in 1960. The panel's

recommendations were that more professional workers were needed, improved genetic counseling, establishment of community based programs, development of preschool programs, expanded federal funds for services, increased employment opportunities for adults who were mentally retarded, legal protection services, and limitation of institutional care to those who were in real need. Federal services went from \$16 million annually in 1955 to nearly a billion dollars in assistance in 1973. Most of this money went for personal maintenance through Social Security payments and medical insurance rather than general program services.

In the 1960s the first attempts were made to depict existing conditions of institutions for mentally retarded persons. Records describe the institutions as fenced, some with barbed wire compounds, the buildings massive and impenetrable, bars and locks on windows and doors, inside and outside the buildings. Reports described gaping holes in the ceilings, urinals ripped out, sinks broken, and toilets backed up. Overcrowding was noted in every institution mentioned. Beds were side by side and head to head, and in some wards it was impossible to cross the room without actually walking on the beds. Many rooms were without pillows, and mattresses sagged with the weight of the residents so that they touched the floor. Many

wards had solitary confinement cells, referred to as "therapeutic isolation". These cells were usually located in the basement, away from casual or official visitors. The cell was usually 7' by 7', and those reportedly observed had no beds, washstands, or toilets. Many residents were seen naked, crouched in the corner lying in their own feces and urine. One record described an incident in which a child was placed in solitary confinement over a long weekend for striking an attendant, while another young resident who had bitten another resident's ear off was punished by being sent to bed early. Children were pictured with their hands tied and legs bound. Reportedly the solitary confinement cells were in use seven days a week, 24 hours a day. One reason cited for the heavy use of the cells was the extreme shortage of attendants. One attendant was responsible for a multi-level ward housing over a 100 severely retarded ambulatory adult males.

These reports in published material were supported by oral histories obtained from staff working in state schools during the 1960s. The oral history obtained from one attendant indicated that they were not only responsible for the care of the client, but also for maintenance of the buildings, laundry, ordering and deletion of clothing for the residents, administration of medications

and paperwork on each client. One attendant's report read, "What can one do with those patients who do not conform? We must lock them up, or restrain them, or sedate them, or put fear into them" (Blatt & Kaplan, 1974, p. 13).

Dayrooms observed had overwhelming stench, the rooms had bleacher benches where unclothed residents sat crowded together without purposeful activity, communication, or interaction. Attendants reportedly were standing around or hosing down the floor to remove the excrement into a sewer drain located in the center of the room. The living quarters were gloomy and sterile with rows of benches where untold numbers of human beings sat waiting. The residents reportedly looked and acted depressed; sitting on the benches, staring at the blank screen on a broken television.

Burton Blatt was one of the early individuals involved in the field of mental retardation, who attempted to raise the consciousness of law makers to the reality of treatment that individuals who were mentally retarded received. He exposed the care and treatment of institutionalized infants and small children in his books and essays. Burton Blatt was at one time a superintendent of one of these institutions. He recalled hundreds of cribs crowded into a single ward, children lying in them, ages one to two,

no human contact, interaction, no toys, no stimulation. Children were observed with severe head lacerations from head banging. It was theorized that head banging was the result of lack of stimulation and could be drastically reduced in settings where children had things to do.

During the nineteenth century the plight of the mentally retarded was shocking almost everywhere in Europe. ...flighty, troublesome or dangerous patients were restrained and kept in a small room or stall in a private house, in lunatic boxes, in cages or in other places of confinement that seemed appropriate for isolating them and rendering them harmless...as a result of poor supervision, many committed suicide, perished through accidents or created serious disturbances. The tense and exasperating environment thus created and encouraged the establishment of the strictest preventative measure.

Emil Kraepelin

(Blatt & Kaplan, 1974, p. 87)

Institutions were physically described as modern well-equipped settings, but psychologically they were hell-holes where patients languished until death. Life was silent and usually spent in bed, they were totally dependent on others to meet their needs. If they complained or became angry, it was looked upon as a personality defect. The time spent in staff-client contact was very slight. Oral histories supported the published statements. The inhumanity was not deliberate; it was the result of staff shortage, but any increase in staff would strain the budget, and the attitude that not much could be done continued to exist.

Burton Blatt (1973) wrote:

...that the State does not own a Man, that the State controls but may not buy or sell a human being, that I may destroy myself but the State has no right to my body or my corpse - nor to my feelings or mind or spirit. ...the State that is permitted by law to take or reduce my life while I - who am the owner - may not, under penalty of fine or imprisonment, take my own life or cause myself bodily or moral harm. The State may with provocation, kill me, institutionalize me, seclude me, shock me, drug me, dirty me, animalize me. But I, who am the owner, may not kill myself, scandalize myself, drug myself, dirty myself, or dehumanize myself. What the State must be prevented from perpetrating must become my inalienable - albeit possibly stupid - prerogative. The State - as it substitutes pills for strait jackets and therapeutic isolation for solitary cells - never changes as it demands that each of us bend and twist as we scrape low to say grace and pay homage to the State. Long live the State and to hell with Man; even - exquisite irony - to hell with each Man who represents the State. Man once manufactured the State, and now the State manufactures Man; the State is now the apotheosis of Man! Possibly Hemingway thought of the State when he remarked, 'All things truly wicked start from innocence'. (p. xxiv)

There was a feeling in the 1960s that it would be disastrous to leave the care and maintenance of the mentally retarded to professionals. It was not believed that professionals were evil victimizers or that they did not want to do what was right. Instead it was felt that they would be easily blinded to injustice and their unwitting role in it. Virtue can be made out of necessity thereby accepting evil. A conflict existed for professionals because of the need for personal comfort and security and the risks of non-conformance with policy and procedure.

They could pledge allegiance to symbols of objectivity while discrediting the opinion of another because of his or her status. Professionals know power corrupts but do not recognize the process in themselves. It is vitally important that professionals, especially those in administrative positions, be controlled against themselves, for their sake as well as those in their overall care. Some controls were established in the form of boards of trustees of institutions, but were basically nothing more than window dressing. It was not believed that professionals were the cause of the conditions in institutions, rather it was felt that everyone played a role. Various professional groups provided the care and determined the standards for care, which was at times counter productive. It was theorized that highly verbal and intellectual professionals by virtue of their own value systems, felt that mental retardation was the ultimate impairment, explaining why there was so little interest in the field of mental retardation by professionals.

By the end of the 1960s more attention than ever before finally began to be paid to the field of mental retardation due in part to the extensive participation of the National Association for Retarded Children. The American Association on Mental Deficiency was revitalized

with increased membership and programs. Universities and colleges became more active in research and training in special education. Professional interest awakened in mentally retarded children. Interest grew in the reform of residential institutions and the development of community resources for diagnosis, evaluation, and training. Forums of direct and indirect concern by advocates for persons with mental retardation were initiated in the 1960s. Emphasis on programs of special education for the handicapped were allocated funds. The parent movement effected a strong impact in the 1960s and the reassessment of mental retardation was based on rapidly developing knowledge. Mental retardation was brought to the forefront of public consciousness. The 1960s set the stage for what was to become a massive national effort to combat mental retardation and a new expression of the needs which had been building an accumulated pressure.

1970

In the 1970s, one after another, state school systems began to be repeatedly exposed. Society was presented with a clearer glimpse of the misery, loneliness, and stench that had existed for so many years. In the summer of 1971, Mark Blazey visited a state school for three days

and produced a photographic essay depicting the segregation and abuse suffered by those members of our society; people viewed as being so different that they required separation from the rest of social culture and the real lives of people. History has demonstrated repeatedly that society does not accept those who are set apart as different. Thus, creation of institutions flourished, operating under the guise of rehabilitation, treatment, and cure. In actuality, the system was the epitome of gross and effective neglect, misrepresentation, and abuse.

Children, as Blazey described them, were out of their cribs usually on floor mats just until their sheets were changed on their beds. When Blazey questioned the staff, they referred to this as being "up for the day". Blazey asked a duty nurse if any of the children would be able to walk, "No, they will never be ambulatory" (p. 24). This reply was reflective of the perception this nurse had that the situation was a hopeless one. When asked how many women were on tranquilizers, the head nurse replied, "-100%, receiving an average dose of 100 to 300 mg. of Thorazine, three times a day, plus 10 to 50 mg. of Valium daily, and 1½ gr. of Phenobarbitol and/or 50 to 100 mg. of Dilantin." Because of understaffing, all the girls not in seclusion were moved into one dayroom and controlled

by the use of camisoles. When further control was needed, they were tied to chairs. Meals were earned by performing simple tasks like washing themselves, dressing, taking medicine, or putting on their bib. If they failed, the food was refused to them. A nurse and two residents were responsible for feeding nine blind residents not allowed to eat with the rest of the residents. The helping residents were then allowed to eat themselves, followed by work in the cafeteria; cleaning trays, sorting utensils, and mopping. They did not receive payment for this work except occasionally an extra dessert. Blazey described a specific encounter with a child lying in a urine-socked bed under a restraining sheet. Upon asking a nurse how long this situation had existed, the answer was 15 years. The nurse stated that she got up for 5 to 15 minutes every day. The child ate her meals while lying flat and neither she nor the bed sheets were cleaned before she ate her meals during the day. An attendant's assistant explained to Blazey that in fact this child only got up on Mondays and Thursdays for a bath. Blazey told how residents were required to ask to use the toilet, then had to wait for an attendant to give them toilet paper to clean themselves. They were not trusted with the toilet paper for fear they would waste it or stop up the toilets. Many residents

had bank accounts at a local bank but did not receive the interest from their accounts. The money was significant and was used by the school to remodel buildings, fund dinners and gifts for employees and volunteers, and pay the sheltered workshop employees (using the interest from their own accounts). No matter the time of the day or night the children always remained in their beds, side by side and head to toe in rows, they were crowded into the wards, and given medications which helped them to sleep.

The Pandora's Box of the state school system had been opened. The philosophy of that system which separated the mentally retarded person from normal interactions with society and relegated them to nonproductivity was exposed. The concept that the institutional system was the final common pathway for all children who were mentally retarded had caused the public to accept institutionalization as the best strategy to deal with the problem. The ideology that gripped the nation was that mental retardation and developmental disabilities were fixed stigmas, were untreatable and worsening, and it reinforced inhuman and antiscientific practices.

Willowbrook was a dramatic and illuminating episode in this time span. Extraordinary efforts were set in

motion to close a scandalous institution and return 5,400 mentally retarded residents to the community. Disclosure of the neglect, abuse, and inhumane conditions began in 1972. After Willowbrook Litchworth, and Rockland were exposed as endpoints of ignorance, irresponsibility, and scientific ruin. The strategy of removing children from society, concentrating them, and offering no hope of return to society was a strategy of those who had no strategy.

In 1970, a change in attitude of society emerged towards people who were mentally retarded. A task force voted to condemn legislation which promoted involuntary sterilization, believing that it was a step toward genocide of poor and handicapped individuals. A declaration for the handicapped was formulated, based upon the belief that all children in the nation had a right to comprehensive health care and that the handicapped child had often been denied this right because of difficulties in meeting his special needs. The principle themes were the right of all persons to exercise a choice in the decisions that affect their lives, diversity of individuals or groups within the common society, equality of life, and concern for human plight. Education was another major concern. Emphasis was on self-actualization as the central value; early detection, and integration into regular school life;

public understanding; continuing research into causes, treatment, and prevention; and advocacy programs; were addressed. A reversal emerged in the tendency to make special education peripheral and make-shift, and maladapted to individual need. The major themes were: (a) Youth Involvement, (b) Community Control/Participation, (c) Equality/Pluralism, (d) Libertarianism, (e) Humanization, and (f) Humanitarianism.

The 1970s were a period that could well be described as the decade of litigation. A number of major court decisions reaffirming that every citizen, even those with mental retardation, had the same right as any other citizen.

Bruce Ennis, a lawyer hired by Aryeh Neier and the New York Civil Liberties Union (NYCLU), helped establish some of the first principles of the mental health law from 1970 to 1972. The roots of this transformation lay in the civil rights movement which culminated in the Supreme Court's decision in 1954 of Brown versus Board of Education. This decision was on the behalf of minorities, the poor, prisoners, and mentally disabled persons. These various groups were encouraged to define themselves as oppressed minorities in search for constitutional rights. The civil rights movement taught them to think of themselves not as poor unfortunates to be pitied, but as competent

individuals who had entitlements. This shift marked a major division in twentieth-century social thinking and social actions by removing protective legislation and replacing equal rights.

Bruce Ennis succeeded in bringing the Constitution behind the walls of asylums. He played a part in court decisions which stated that when a person diagnosed as mentally ill was not automatically judged incapable of standing trial; that patients did not lose all their rights when entering a mental hospital, thus making it difficult to impose unwanted treatments on patients. The most notable litigation was on the behalf of patients' right to treatment. Bruce Ennis, George Dean, and Charles Halpern conducted a trial before federal judge Frank Johnson in the case Wyatt versus Strickney, (later changed to Wyatt v. Aderholt), which produced 49 standards dealing with the care, treatment, and habilitation of people who were mentally retarded. Some of the court ordered items were:

1. minimum staffing ratios for both professionals and non-professionals;
2. minimum standards of safety;
3. payment for residential labor;
4. individualized plan of treatment for every resident, with periodic review;

5. standards for sterilization;
6. controls on behavior modification techniques and on drugs used to change behavior;
7. no experimentation on retarded residents;
8. emphasis on release to the community, with appropriate planning; and
9. treatment of all persons in the least restrictive habilitation setting.

The Wyatt case served as a basis for other law suits against institutions. In 1972, the New York case against Willowbrook focused upon the need for maintaining the least drastic measure of treatment. The results disallowed seclusion in isolated rooms, straight jackets, and drugs that would restrain their activity without proper supervision. The court order also called for the reduction of the total population of the institution of 5,400 clients to 250 or fewer within six years.

Ennis had a deep distrust of custodial institutions and he instinctively thought of inmates not in clinical categories but as citizens. He did not agree that making a distinction in the degree of mental retardation was the way to ration out constitutional entitlements. Ennis began to learn about normalization theory and found it completely congruent with his own position. Both the

professionals and the litigators wanted to integrate people with mental retardation into the community while avoiding stigmatizing labels. He met many leading practitioners of normalization in the field of mental retardation who taught him a most critical lesson about the institutionalized individual; the gross disabilities, bizarre behaviors, twisted limbs, and head banging were not the reason for incarceration but were instead the result of incarceration.

During the 1970s the right to an education became another major legal issue. A free public education was provided for most Americans, but a large number of people who were retarded were for many years denied access to educational programs. The Pennsylvania Association for Retarded Citizens argued that the Fourteenth Amendment of the Constitution required that all children have equal access to public education and the right to due process of law. More than 14,000 children in Pennsylvania were being denied a public school education. The courts ruled that all children, regardless of their ability were entitled to a free public education. The courts also ordered that the state of Pennsylvania identify and provide all previously excluded children between the ages of 6 and 21 with an appropriate education. The next school

year 10,000 children were enrolled into the public schools in Pennsylvania for the first time and 200 new classes began. This Pennsylvania court decision had tremendous impact nationwide. Shortly, other states were legislating that all children were entitled to free public school education. By 1974 the federal government officially endorsed the idea, and Public Law 94-142, the Education of All Handicapped Children's Act, was enacted. It was intended to provide federal formulas for funds to encourage the states to offer education and training to all handicapped children, regardless of the severity of their handicap. The Vocational Rehabilitation Act of 1973, (P.L. 93-112) provided state grants for the creation of educational, employment, and independent-living services for people who were mentally retarded as well as for other disabled persons in the community. Federal legislation finally provided financial support for the development of community service systems; funding being an important prerequisite to the implementation of social policies.

1980

Technological advances have had an impact on the lives of physically and mentally disabled persons. Electric wheelchairs, artificial limbs, robotics, and communication

information systems have the potential to improve the lives of people who are mentally retarded.

The second generation of anti-institution litigation seeking to close institutions and order states to develop community care systems for persons with mental retardation was in progress. The Third Circuit Court of Appeals ruled that under the Developmentally Disabled Assistance and Bill of Rights Act of 1974, there was a clear preference for a legal right to habilitation in the least restrictive alternative. It also affirmed a preference for habilitation of mentally retarded persons in the community as a matter of legal right, having a significant impact on deinstitutionalization of mentally retarded persons.

The deinstitutionalization and mainstreaming movements represented ethical requirements to integrate mentally disabled persons into society. Disabled persons have been one in a series of minority groups who in the last two decades have sought equal opportunity in all aspects of living. Progress has been slow and has encountered and continues to encounter a number of barriers. Society is imbued with ethical, racial, class, and sex discrimination. Despite continued declarations of social injustice, contrasts in the quality of life can be witnessed in our schools, neighborhoods, and health care facilities and

services rendered. Little wonder that integration of mentally disabled persons, formally segregated from the social structure, is meeting with resistance.

Implementation of the normalization principle has been successful in the Scandinavian countries but failure in the United States has been predicted by Zipperlin (1975).

"It is hard to integrate anyone, normal or not, into a disintegrating society based on egotism.

Deinstitutionalization does not constitute normalization unless it goes together with the use of some appropriate, integrated structure" (p. 271). Kurtz (1977) also believes that true social integration of mentally retarded persons is doubtful:

At this point one can only speculate about whether the American public is ready to accept the drastic changes in social patterns which implementation of the normalization principle would necessitate. There is little doubt that the public would be willing to accept the principle on a theoretical and idealistic level since it is consistent with the general American value system, but it may not be willing to make the practical everyday adjustments which would be necessary if it was to be implemented in social and economic activities. (p. 141)

Pessimistic sentiments are confirmed by continued neighborhood resistance to housing mentally retarded persons within the community. Without a sense of community, disabled persons may choose the course of other minorities who have grown impatient with integration and seek separate,

high-quality living somewhat like the planned community living models in Europe.

In 1981 Carl Haywood addressed the American Association on Mental Deficiency to discuss the wide variety of negative social forces to which the mentally retarded person is vulnerable, most of which limit personal and psychological development and access to total participation in the social structure. Some of the negative social forces Haywood covered were: labeling of any person as mentally retarded, residential segregation, dependency on others, and decisions made that may result in death. Wolfensberger (1980) shared a concern that there may be a new wave of euthanasia with severely impaired people. When economics tighten, fiscal policy may dictate moral and ethical judgments. Congress established the Select Committee on Children, Youth and Families in the House and the Children's Caucus in the Senate, but it is not enough to simply draw attention to the needs of disabled persons and their families.

Hauerwas (1982) asks why society thinks people who are mentally retarded should be cared for, or why they need to be singled out for special care, or what moral presuppositions inform society's understanding of mental retardation, or why parents should have the primary responsibility. Hauerwas believes first society needs

to understand what role people who are mentally retarded play in our lives. Society needs to understand why it should care and exactly who are the mentally retarded. Retardation often denotes a lack of certain skills valued by society, which might go unnoticed in another society. How, can discrimination, for or against mentally retarded persons, be justified. The moral implications of even talking about the problems confronting mental retardation assumes ethical presuppositions. The civil rights movement argues that they should be treated like anyone else. However, people who are mentally retarded do have certain problems that it is assumed, should receive special care and attention, not just equal attention. The issue then becomes how society can treat persons with mental retardation in a manner that does justice to their particular problems without providing this special form of care.

History of Mental Retardation in Texas

There is little recorded about individuals with mental retardation during the 1800s in Texas. Austin State Lunatic Asylum opened in 1861 and references appeared outlining a 1856 law stating: "No idiot who can be safely kept in the County to which he belongs...shall be sent

to the Asylum." Regardless many individuals who were mentally retarded were admitted along with people who were mentally ill. There was continued disregard for the law, and mentally retarded persons were not segregated from the criminally insane. In 1897, B. M. Worsham reported to the Governor about the tendency to place all classes of people together in the Asylum. Worsham remarked that it did not matter whether they were old or congenitally defective if they were placed in the asylum. He felt this overcrowding was due to no established institution for "idiots, imbeciles, and epileptics". Worsham felt that placing mentally retarded persons with insane persons was a great detriment to the insane. He felt the needs of insane people were not being met while they were associated on wards with mentally retarded people.

In 1899, the State Epileptic Colony, under the supervision of the San Antonio State Hospital was authorized. In 1904, the Colony opened in Abilene. An administration building, two chapels, an occupational therapy building, a sewing room, power house, ice plant, bakery, and mattress shop were on the grounds. The colony was changed in 1925 to Abilene State Hospital. The hospital's biennial report for the years 1924-1926 recorded

the average number at about 780 inmates cared for at an average cost of 74 cents per capita daily.

Treatment was described in which the younger patients attended school consisting of basket making, needle craft, and rug making. Sunday services were held regularly. It was reported that all was done with the patients in order to have as few paid employees as was safely possible for the welfare of the institution. In 1957, the facility began serving mentally retarded individuals and the name was changed to Abilene State School. Reportedly the name of the institution changed, as did policies regarding admissions, but such revisions did not alter people's attitudes. By 1959 it supported a population of 1,450 of which 900 had a diagnosis of "epileptic" with all levels of intellectual ability, along with some 50 overly psychotic individuals.

Provisions for the education for unaffected children and epileptics had been made by the early 1900s, but education for the slow or mentally retarded child came slowly. In Texas' early history, care for affected children was in their own homes by their family, county poor farms, community jails or in institutions funded by charitable groups like the Salvation Army. As the state population grew so did the number of citizens

requiring specialized care. As the need of specialized care became more clearly defined a first bill was passed for their care, but it was vetoed.

Ice Berg Reeves and D. S. McMillan in 1915 passed House Bill 73 advocating a home for the feeble-minded. Governor Jim Ferguson signed the bill which became effective in June 1915. A State Colony for Feeble-minded, officially opened in Austin on October 31, 1917 with a capacity for 65 students. John Westly Bradfield, M.D, who was the first superintendent of the Austin State Hospital, was named the first superintendent of the State Colony for Feeble-Minded. The institution's name was officially changed to Austin State School in 1925. Entrance requirements for the school was that the person be judged feeble-minded by a county court of Texas. Only females were admitted the first year. An I.Q. of 80 or less and ages between 6 and 49 were additional requirements.

Files kept by Bradfield evidenced that the school faced major shortages: A lack of dormitory space for residents of Texas needing to attend such a school, a shortage of teachers trained to work with mentally retarded students, a shortages of funds for expanding facilities to meet school needs, and a minimum availability of equipment designed for training in this type of school.

Bradfield wrote a report in 1920 to the State Board of Control regarding separation of males and females stating: "Experience in other states has shown the folly of associating the two sexes at the the same institution, and I strongly urge upon you gentlemen the wisdom of complete sex segregation". Bradfield also advocated institutions as permanent residences for individuals with mental retardation. He wrote:

The problem...is the high grade moron. The female...is, as a rule, quite unmoral, and makes no effort to protect herself. Her children, usually illegitimate must, as degenerates, criminals, or defectives, eventually become wards of the State. The male moron is also a potential criminal, and is the class from which inmates for our jails and reformatories are recruited. Their segregation and control, though life, is the remedy. This can be obtained only by legally committing them to an institution where they can be kept permanently.
(p. 25)

Early workers explained that in the wards where most of the patients were not trainable, the children were animally cared for and kept clean. Trainable children did school work and performed chores on the farm, laundry work, and simple manual labor. Employees were on call 24 hours a day. They taught the children, cared for them, supervised them, and took them to church.

The Legislature reappropriated \$92,000 in 1933 of Austin State School's funds to purchase land east of Austin

for a farm colony for feebleminded adults which opened in 1934. Residents were admitted from Austin State School's population that was not able to benefit from education. Admission until 1973 was limited only to adult males. Employees in the 1930s worked 12 hours one day then 14 hours the next day for 30 consecutive days before having one or two days off. They were required to live on campus, curfew was at 10 p.m. and employees could only marry with the sanction of the superintendent. One long time employee recalled that the boys ran away often because they were locked up all the time, and if someone in their care ran away they were fired. Long time state school employees recalled the 1940's as a time when parents were only allowed to visit their children in the administration building, not in the dormitories. It was reported that at that time more of the residents were delinquents or mentally disturbed rather than retarded individuals. Reportedly there was no magazines or toys in many of the dormitories and the residents spent the day sitting on benches.

Employees wore uniforms, long sleeved gray dresses with names embroidered in red for woman and white outfits with black ties for men. The buildings were locked and barred to control residents who tried to run away. The main gates were locked at midnight, salaries were low,

less than \$200 a month and hours were long. In 1945 special education classes for learning disabled children began in Texas public schools. Mexia State School was converted from a German prisoner of war camp in 1946 to accomodate the increasing need for residential facilities. By 1951 state school residents amounted to approximately 3,000 residents and more facilities were needed. Abilene State Hospital became Abilene State School in 1957, Denton State School was opened in 1960, Lufkin State School was converted from a U.S. Air Force radar base in 1962, and Austin Farm Colony became independent and its name was changed to Travis State School.

A change evolved in the philosophy of the care and treatment of the mentally retarded with the addition and expansion of schools. The state schools warehoused mentally retarded people using the custodial approach. This approach was replaced by an emphasis on developing each person's potential through recreation, education, social training, and occupational skills. Waiting lists for admission lengthened as improved medical care prolonged life span and a growing statewide population increased the number of mentally retarded persons requesting residential care. The state schools reported nearly 10,000 residents by 1962. One attendant reported that black clients were not admitted

to the state school until 1969. Black employees were hired to work only on the severe and profoundly handicapped dormitories, not on ambulatory ones. It was also reported that many of the employees were couples, husband and wife teams, and initially no one under the age of 30 was hired to work directly with the residents.

In 1950 the National Association for Retarded Citizens led a nationwide movement which spilled over into Texas, to improve facilities, programs, and opportunities for mentally retarded persons. An increased awareness was emerging along with an improved understanding of what individuals with disabilities were experiencing. A more accepting public attitude was emerging. Beginning in the 1960s citizen planning groups were appointed to survey the state's mental health and mental retardation needs. These citizen groups instigated passage of the Texas Mental Health and Mental Retardation Act (H.B. 3) in 1965. House Bill 3 provided legislation to create the Texas Department of Mental Health and Mental Retardation. The newly formed department took over responsibilities which were formerly under the direction of the Board of Texas State Hospitals and Special Schools. The legislation also authorized creation of local boards of trustee to organize and administer community mental health and mental retardation

centers. The legislation stipulated terms under which state grant-in-aid funding could be allocated to the community centers by the new department.

In 1967 there were 27 community centers established in Texas providing services to more than 80% of the state's population. Community centers utilized grants-in-aid, funds from federal grants, client fees, and local, public, and private sources. Comprehensive programs included diagnosis and evaluation, outpatient treatment, brief hospitalization, family and group counseling, sheltered workshops, consultation and education, alternate living facilities, and a variety of services designed to treat and prevent mental impairments.

Amarillo and Beaumont State Centers for Human Development opened in 1967 with satellite classes in 1968. El Paso State Center began operating in 1975. The need for additional state schools and reduction of waiting lists culminated in five more schools opening: Richmond in 1968, Lubbock and San Angelo in 1969, Corpus Christi in 1970, Brenham in 1974, and Fort Worth in 1976. A school was authorized but not funded for San Antonio.

State hospital population dropped from 16,000 patients in 1966 to less than 8,000 in 1975. The newer schools were constructed under the systems approach, which was

economical, modular, and allowed for structural changes for specific programs. The trend was toward smaller facilities with more homelike living environments as a part of normalization, emphasizing living conditions that were as close to normal as possible. Community programs served moderately retarded individuals in the 1970s while residential facilities served more severely retarded and multi-handicapped individuals. State schools and community services programs still needed to integrate services to provide continuity of care.

Development of school sponsored outreach programs slowed admissions and supported residents returning to the community. There was an increased number of extended living facilities helping residents that met criteria return to the community and acquire independence. In 1974 there were 13,000 residents in state schools.

Behavior management techniques became important training tools at state schools; programs offered included recreation, speech, physical and occupational therapy, vocational and academic training, sheltered workshops, and self-help and social skills classes. In 1974 genetic counseling and the Behavioral Characteristics Progression were initiated to improve services to the mentally retarded person and their family. Litigation began to

focus public attention on the plight and the constitutional rights of mentally retarded persons. Two law suits had great impact on Texas delivery of services. The first was Jenkins versus Cowley; a lawsuit filed by Dallas Legal Services in April, 1974. It alleged that hospitals failed to provide the least restrictive environment, were understaffed, over medicated clients, and provided only the most oppressive and unhealthy living conditions. The next law suit was Lelsz versus Killian filed against the schools in December 1974. This was later changed to Lelsz versus Kavanagh and it was settled in December of 1983. This law suit created many changes in delivery of services in the state of Texas and is still impacting that care today. The Fair Labor Standard Act in 1973 mandated that minimum wages must be paid to working residents of institutions and was a foundation for both cases.

State schools were once certified by the Joint Commission on Accreditation of Hospitals which set optimum standards of care and treatment; however, there was no built-in incentive plan, like withdrawal of funding, if standards were not met. Today state schools are certified by Intermediate Care Facilities for the Mentally Retarded (ICFMR) which qualifies them for Title XIX Medicare funds

under the Social Security Act. The Texas Department of Mental Health and Mental Retardation (TDMHMR) is under federal standards and guidelines for licenses. There are currently 22 surveyors making up five teams that cover the state of Texas. They make two unannounced visits to TDMHMR facilities each year monitoring 700 standards. Each facility is given a vendor number for reimbursement on each 180 day level of care. There are sanctions levied if facilities do not meet those standards during an audit or survey. Facilities in Texas are under the Active Texas Model of care demanding that each individual in it's care receive an individual program plan (IPP). Goals are stated with measurable objectives and a monthly review, which is a management by objectives approach. Prior to ICFMR and the Active Texas Model, management was simply custodial, which meant residents were all treated in an institutional manner, ate the same food, wore the same clothes, and had their hair cut the same way. Since the Active Texas Model there is more individualization, right of client privacy, and service changed with the training and medical components more individualized to meet specific needs. One Program Specialist felt that sanctions had helped to guarantee that standards were met in order to allow the Active Texas Model to work, but that class action

law suits had more impact on normalization for mentally retarded persons. No longer can 1,200 bed facilities be built. Smaller units of preferably four but not more than six beds is the rule for all new group homes built in Texas now. The Texas Senate in 1981 recommended that legislation be enacted to prohibit the placement of a child in a child care institution for more than 60 days without a court order. TDMHMR developed continuing procedures to assess the residential placement needs of current and potential client population in both institutional and community based setting.

Over View of Institutions

The number of mentally retarded individuals in state institutions increased throughout the years, yet there was no proportional increase in the amount of money allotted to operated these programs. State legislatures were not prepared to both build more institutions and provide the funds necessary for hiring adequately qualified staff to properly manage the programs. Therefore, many state institutions incarcerated the mentally retarded person in dehumanizing conditions. They were treated as objects, and to use Wolfensberger's (1975) term, they were "warehoused" with almost total disregard for their rights, their feelings, their fears, or their hopes.

The public cared little about what took place behind institutional walls. Many publically supported state institutions truly became examples of gross neglect. Institutional administrators received little equipment and funds for the maintenance of necessary operations. General attitude was that people who were mentally retarded were hopeless, helpless, and burdensome. State legislatures primary interest was to provide for an absolute no frills living arrangement. This lead to overcrowded living conditions, nonexistent treatment programs, few recreational or social activities, and almost no individual privacy. Society's negative attitudes toward people with mental retardation was primarily responsible for the isolated locations, poor physical conditions, and limited quality of programs.

Wolfensberger (1975) described eight perceptions of mentally retarded persons that could impact the treatment that they received in institutions throughout this country. The first seven are negative giving rise to the dehumanizing treatment they received in institutions for so long.

1. The retarded person as sick
2. The retarded person as a subhuman organism
3. The retarded person as a menace

4. The retarded person as an object of pity
 5. The retarded person as a burden of charity
 6. The retarded person as a holy innocent
 7. The retarded person as the butt of merriment and ridicule
 8. The retarded person as a developing individual
- The eighth perception is much more optimistic, and considers people who are mentally retarded as being capable of improving their behavior and with proper assistance; that is, they can grow, develop, and learn. When this concept is used as the basis for care and treatment, staff interact to encourage the residents involvement with his or her environment. The person who is mentally retarded is provided with personal responsibility. Living conditions are more normalized and surroundings tend to compare favorably with the surroundings of non-retarded individuals who live in the community. This approach views people who are mentally retarded as less deviant and efforts to compensate for whatever differences do exist is done through the provision of adequate services. Emphasis in recent years has been placed on seeing these people develop as individuals. This altered view of mentally retarded people has changed the ideas about the kinds of residential programs that should be designed to serve

the needs of these people. Many professionals concerned with institutional care believe at least three needs must be met in all residential programs: (a) the need for privacy, (b) the need for independence, and (c) the need to be treated as an individual.

Deinstitutionalization

Since the end of World War II, the United States has sought to formulate a social policy designed to improve the care and treatment of mentally retarded persons. Only in recent decades have such terms like deinstitutionalization, normalization, and mainstreaming signified an ideological shift in policy.

Deinstitutionalization is a sociopolitical movement with both physical and psychosocial connotations. The underlying belief is that community care will improve the quality of life for mentally retarded persons. Deinstitutionalization means quite simply that mentally retarded persons will be moved from large institutions. The ultimate goal is to enhance independent functioning and social participation of mentally retarded persons.

The institutional population peaked in 1969 and 1970 when it topped 200,000 residents in the United States. The numbers declined steadily to 165,000 residents in

1975, and by 1979, had dropped to 133,400. Residential population was estimated to have been reduced to 94,000 in 1985. Deinstitutionalization has a fourfold purpose (PCMR, 1976): To provide sufficient variety of living alternatives in local communities, adequate services for maximum personal development, freedom and quality of life, and to eliminate institutions in order to serve specialized training functions.

Deinstitutionalization and mainstreaming movements represent moral imperatives to integrate increasing numbers of mentally disabled persons into our social network. Disabled persons are but one of a group of minorities seeking equal opportunities. However, it may not be the humanitarianism or the enlightenment expressed in the normalization principle or the moral imperatives of legal advocacy that result in formulation of deinstitutionalization policy, but rather inflation, budget cuts, and cost-effectiveness. Early studies indicated that community care would be more cost-effective than institutional care, resulting in increased momentum for deinstitutionalization.

Implementation of this policy resulted in dramatic decreases in the number of new admissions to public institutions for mentally retarded persons. It was

estimated that in 1970 there were 16,000 new admissions, in 1980-1981 there were only an estimated 5,547 new admissions. This is a 66% decrease attributed to declining birth rates in 1980 and stringent civil commitment procedures, as well as an effort to place more mentally retarded persons in less restrictive community settings. In an 11 year period between 1970-1971 and 1981-1982, institutional populations decreased from 189,546 to 119,335 representing a 37% decrease. By 1985 it is estimated that populations decreased below 100,000 residents. The rate is expected to slow since there is great difficulty in developing adequate community alternatives for persons with severe and profound retardation.

There was no accurate data obtained in institutional readmissions, but it has been estimated at between one percent and 30 %. Maladaptive behavior unacceptable in community living was most frequently associated with readmission. However, inadequately trained staff to deal with problems as they arise, and community resistance were also mentioned as factors for readmission. Stress was the major cause of behavior problems, and because of the difficulty in dealing with them, many problems must be overcome if the deinstitutionalization policy is to prove successful.

Counterforces impeding deinstitutionalization policy may create a backlash in formulation policy. A recent Supreme Court decision reversed an earlier decision that required states to provide appropriate treatment in the least restrictive environment. A second Supreme Court reversal stated that institutionalized persons do not have a mandated constitutional right to habilitation, rather it was preference.

The courts have also noted that professionals in the habilitation of mentally retarded persons differ strongly about the effects of training on severely and profoundly retarded persons. There is a movement by some to categorically limit the rights of habilitation in least restrictive environments to some groups of mentally retarded persons.

Resistance to group homes was encountered by nearly one half of those homes built. Neighborhood groups voiced concerns that property values would fall, that "these people" are dangerous, and that the character of the neighborhood needed to be preserved.

Congress has cut back federal funding of social programs like those that assist mentally retarded persons living in the community, and lets the state decide which disadvantaged group benefits from the funds that are

available. Under Title XIX (ICF/MR) large amounts of funds were allocated to construct and maintain public institutions, small sums were invested into the development of alternative community residences. Quality community care is not cheap and for some types of clients it may be more costly. President Reagan's new federalism proposals and support to balance the budget places an even heavier burden on states to provide adequate services. Without the federal role in the support of these services, there will be a wider disparity among state in the care of mentally retarded persons.

In many cases to expedite deinstitutionalization requirements residents were dumped into the communities which were unprepared to provide adequate services. Financial and physical exploitation of mentally retarded persons living in the community has caused many parents to reconsider their support of deinstitutionalization policies. The absence of a convincing data base to support the assumption that community care improves the quality of life for mentally retarded persons has caused many professionals to declare a moratorium on deinstitutionalization until research can be conducted. Attempts to provide greater equality by integrating mentally retarded persons into society must be directed

by a moral "guiding beacon" that will not be easily overcome by resistance or early failures.

Mainstreaming

Mainstreaming today is used to refer to the integration process of handicapped children into public schools, but it was not long ago that the term was used to identify efforts by ethnic and minority groups to receive equal educational opportunities here in the United States. Legislation has had significant impact on social policies to integrate these racial minorities into the American school system. Regular classroom teachers complained that these children were difficult to manage and that they impeded the educational progress of the other children. The solution was to create ungraded special classes, which soon became the refuse pile for truants, discipline problems, backward children, and non-English speaking children. Eventually auxiliary schools or centers were built to house the special classes and one school system became two systems, one for regular pupils and the other for special pupils. With the invention of intelligence tests a dramatic increase in the number of immigrant children and minorities were being labeled as morons and assigned to these special self-contained classes, called "fool classes".

Legislative pressure brought on by parent groups and professional advocates, resulted in schools assuming the responsibility for educating moderately retarded children in the 1950s. Children classified as profound and severe were excluded and remained at home or were placed in state or private institutions.

During the 1970s parents of retarded children became increasingly disenchanted with school practices that resulted in poor quality instruction or total denial of instruction. Minority parents viewed the labeling and segregation into special classes as racial discrimination and an attempt to reestablish the old separate but equal education. Parents viewed total exclusion of their mentally retarded children from public schools as a denial of the constitutional rights of their children. The parents of mentally retarded children united with other parent groups at the local, state, and national levels to express their grievances in a unified louder voice. The movement stimulated public awareness of the inadequate educational treatment their children were receiving, and the parents began to exercise political power in order to effect educational policies at all levels of government. The services of attorneys were secured to force changes in

the school systems which had denied their children equal educational opportunities.

In the 1970s litigation was initiated to obtain the right of education for those mentally retarded children excluded from school and to reverse all alleged discriminatory testing that placed disproportionate numbers of minority children into special classes. A right to education encompassed five essential elements: (a) free access to publicly supported programs of education, (b) proper testing and classification of children, (c) appropriate educational programming, (d) placement in the least restrictive educational alternative, and (e) parental procedural due process (Zettel and Ballard, 1982).

The Education of All Handicapped Children Act of 1974 (P.L. 94-142) is a federal mandate to state educational agencies to develop a plan to provide a full educational opportunity to all school age handicapped children. The preamble of the Act reads:

It is the purpose of the Act to assure that all handicapped children have available to them a free appropriate public education which emphasizes special education and related services designed to meet their unique needs, to assure that the rights of handicapped children and their parents or guardians are protected, to assist State and localities to provide for the education of all handicapped children, and to assess and assure the effectiveness of efforts to educate handicapped children. (Sec. 601)

Any state failing to provide education for all handicapped children may result in the federal government withholding all federal support for education. P.L. 94-12 requires that certain standards be followed when administering psychological tests. It also requires that an individualized educational program be provided.

P.L. 94-142 also defines the due process, which parents of handicapped children are entitled, as being receipt of written notification before the evaluation, classification, or placement of their child; the right to an impartial hearing to challenge administrative decisions; access to all relevant records; and ability to obtain an independent evaluation of their child. Federal assistance needed to alleviate the increasing demands for special education services was included in P.L. 94-142.

The deinstitutionalization and mainstreaming movements during the 1970s complimented each other and each held landmark legislation and litigation decisions that impacted mentally retarded persons.

Deinstitutionalization and mainstreaming are both supported by the same principles. Normalization, the developmental model, and the least restrictive alternative are all principles providing a common focus for both movements. Mainstreaming without deinstitutionalization

would be an empty concept. Those that would have been placed in institutions will benefit from social and educational integration. Deinstitutionalization without mainstreaming would have been nothing more than dumping mentally retarded persons into the community absent of special education services. Therefore, the availability of special education services for all mentally retarded children is a necessary prerequisite to preventing institutionalization. The demand for educational resources is increasing as more mentally retarded children are remaining in the community. The advancement of public policy is essential in both deinstitutionalization and mainstreaming if the long term welfare of the mentally retarded person is to be served.

Sheltered Workshops

Employment services are needed by developmentally disabled people in community settings if deinstitutionalization is to be a reality. The most important type of service is sheltered work experience centers where groups are supervised in work performance and where placement or job counseling, and various forms of work training are available.

Historically, sheltered workshops probably developed from the sixteenth century hospices of the Society of

St. Vincent de Paul. Sheltered workshops for people who are mentally retarded are work oriented programs that have been established to help them achieve as near normal vocational capabilities as is feasible, considering the degree of their handicap. The sheltered workshop provides market-based employment opportunities and training in a protective, less competitive setting than would ordinarily be found in the work world.

The Question for the 80s

The question for the 80s is, who is to speak for the mentally retarded person? Handicapped individuals who are wheelchair bound and uneffected by mental deficiencies can let society know what they need, they speak for themselves given a means to communicate. There is a compelling problem with anyone claiming legitimacy to speak for individuals who are mentally retarded.

Professionals are conditioned to look at the care of mentally retarded individuals in terms of administration and State Development of Hygiene standards and regulations. Professionals are evaluated by fellow professionals; professionals help other professionals and they usually do not go public. As in other self-regulated professions, such as the legal profession, problems from within the group are dealt with as quietly as possible.

Benevolent societies are usually a demonstration of a desire to do "the right thing" for mentally retarded persons. However, the track record of the benevolent towards persons with mental retardation is worth remembering. The degree to which the right mindedness of our fellow humans is demonstrated is a reflection of the degree of right mindedness of the community, suggesting that communal goodwill is prevalent over the concerns of persons with mental retardation. Communities not wanting integration in their neighborhoods demonstrate, even with all their disclaimers of "nothing against these people but--", that they are really in favor of their own perception of what is good in their community first, when dealing with issues concerning mentally retarded persons. Benevolence under the pressure of financial constraints can result in destructive forms of care.

Parents are easily lead and guided by manipulating professionals and their opinions. Making decisions for and about the mentally retarded person is difficult and complicated when parents rely too much on others to help in decision-making. Even though parents are usually honestly concerned about their children who are mentally retarded, they are less than capable of speaking for them

because they are easily intimidated and fear recrimination for the child if they protest policies and procedures.

Attorneys to a certain degree are appreciated when they begin to speak for persons with mental retardation. The civil rights movement trained attorneys to speak for minority rights and broke through to began a new system through class action law suits. There is now a new group of professionals thinking in terms of integration via normalization. These professionals are impatient with segregation and institutionalization. They look at mentally retarded persons as a client population and are not interested in the distinction between the levels of retardation. They simply view them as clients and citizens with entitled rights. Attorneys have a general skill in the area of establishing the rights of persons with mental retardation, but no special skill in meeting their needs beyond those rights. Attorneys are working with the clients as a group, but it is unclear to what intent the good of the group will serve the needs of the individual.

Advocates, such as lay advocates, non-professional lawyers, immediately self-interested parents, or professionals from many fields may not be the solution to speaking for individuals who are mentally retarded.

The concept advocacy is that an individual is to assure the availability and accessibility of the best possible service programs to meet the clients needs. An advocate should be a mature competent person representing the interests of an impaired individual as if they were his or her own needs. Advocacy provides three basic but separate types of services:

1. The advocate for instrumental needs may provide help to the individual in finding solutions to major problems. This type of advocate does not necessarily form a close emotional relationship with the client being served, but does act on behalf of the client in the capacity of a concerned monitor who has not been appointed by the courts.

2. The advocate for expressive needs may act as a friend, entering into a close emotional relationship with the client. This role is referred to as an advocate-friend.

3. The advocate for both instrumental and expressive needs performs some of the functions of a monitor but also develops an advocate-friend role.

With advocacy there is burn-out, lack of knowledge on all issues and details involving specific issues, and there is the non-relenting system. The major concern

is that dollars are available for various federal programs for protection and advocacy, and speaking for mentally retarded persons could become superficial and politicized.

There is not a clear answer for the questions of who should speak for people who are mentally retarded. History has shown us that no one group is free of difficulty in making decisions regarding the care and treatment of mentally retarded persons to be truly their spokesperson.

The current role of the nurse as patient advocate is easily assimilated into the above service type. Nurses are performing as client advocates when dealing with people who are mentally retarded to the fullest extent of their professional duties. The nurse as the advocate may be the direct source of care or may seek appropriate care with other providers through referral. The nurse is concerned with all environmental factors affecting the client and may intervene at any level of prevention. Therefore, the nurse as an advocate plays a very active role in monitoring overall activity and immediately provides intervention when needed to maintain the well-being of the client. The role of the nurse in the future can be a dominant one. Professional nursing finds itself in a position of leadership. Society has long respected

the professional nurse and a responsibility exists to project a positive attitude and image in serving mentally retarded persons. Providing positive professional role models for all to see and follow will enhance a truer understanding of how mentally retarded persons are to be cared for and treated. As professional and human beings deeply ingrained in discriminating attitudes, we must understand where the mentally retarded persons have been and what they have recently emerged from, as well as the high mountains they still have to scale if permanent intergration into the social structure is to occur before the end of this century.

On Man Alone

While he's alone, and while we're together,
Most of a man's time is with but himself.
He is born alone,
And he'll go alone.
Amid the trumpets of life and the drums of death.
In joy and gloom, he is and he'll be but one,
Alone.

There's color and liveliness and zestful things,
To entice and seduce the mind and the heart.
But a man has pride,
As he resists his relatedness.
A man does engage himself in the swirl of life
With three billion others with him here,
And with each alone.

While each one comes,
And as each stays,
And goes,
Alone.

Burton Blatt

CHAPTER V

SUMMARY OF THE STUDY

God hath chosen the foolish things of the world to confound the wise; and God hath chosen the weak things of the world to confound the things which are mighty. (1 Corinthians I, 27)

Selected Factors

Historically, people with mental retardation have been subjected frequently to unequal treatment under the law. They have been excluded from potentially helpful programs and have received inappropriate, inhumane treatment due to social discrimination. Maltreatment and unsuitable institutional confinement have been the major consequence of this discrimination. Lack of accessibility to equal educational opportunities in public schools, denial of self-determination due to oppressive guardianship, subjection to involuntary sterilization, and prohibition of marriage are just a few examples of the violations of rights of people who are mentally retarded throughout previous decades.

Not until the 1970s did any attempt to guarantee that mentally disabled persons receive the protection of their legal rights be enforced under the law. Legislation in

the United States Congress and litigation in the courts caused dynamic changes during this decade in the lives of mentally retarded persons.

The rights of all citizens fall into three categories: the right of citizenship, the right to due process, and the obligation of society to protect the rights of all, including the persons with mental disability. Personhood must be restored or society has failed in its basic human obligation to the person with mental retardation.

The right of life is the first right to be denied. The mentally retarded person has the right to life, the right to be born, as much as any other human being. Even though the right of life is not an absolute right, the principle remains the same, and this right must be equal to that accorded any other person.

Legislation, in the not so distant past, has allowed experimentation, sterilization, institutionalization, and even destruction of mentally retarded persons for the welfare of society. Such legislation bastardized the moral principles upon which this country has been founded. Society has the obligation to value and nurture above all the moral principles which teach us that all human beings are equal in law and that every human being must count as one whole person.

Since 1971 the federal courts have had a tremendous impact on residential facilities, their policies, procedures, and programming. Prior to the 1970s admission criteria and practices in public residential services were determined primarily by individual states. Each state continues to be the authority and the accountable party, even though various court decisions have set the parameters within which each state must operate. Judgments rendered by the federal courts involve an interpretation of the Constitution and its provisions. The Constitutional amendment cited most often on behalf of the individuals with mental retardation is the Fourteenth Amendment.

Section one reads:

All persons born or naturalized in the United States and subject to the jurisdiction thereof, are citizens of the United States and of the State wherein they reside. 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 to equal protection of the laws.

The most important clauses are "due process" and "equal protection". In other words, no individual can have his civil rights denied without the full sanction of the courts, and then only when all procedural safeguards have been assured.

Litigation has been used successfully to clarify the rights of persons with mental retardation. Court

decisions have stated clearly the principle that no person, regardless of intellectual limitations, shall be denied the right to live in a free and open society, under full protection of the law, and that assurances must be maintained that appropriate care, treatment, and training are provided. Actualization is still unsure, and society must come to terms with its obligations, realizing that citizens with mental retardation have suffered at its hands in times past. Society must be ever wary that history does not repeat itself once more as it has done so many times.

"Am I my brother's keeper?" (Genesis IV, 9)

The following tables list various items related to the person who is mentally retarded. They deal with rights that have been denied on occasion, presidential decisions, legislative action, litigation involving institutional reform, education laws passed, and court cases concerning public school education.

Table 1

RIGHTS SOMETIMES DENIED TO THE RETARDED PERSON

Rights of Citizenship

- Right to education
- Right to hold a job
- Right to life and survival
- Right to privacy
- Right to manage one's own affairs
- Right to self-direction
- Right to vote
- Right to habilitation and training
- Right to worship
- Right to marry
- Right to have children
- Right to hold a license
- Right to be paid for work
- Right to medical treatment
- Right to live in the community
- Right to fail

Protection of Due Process

- Right to be represented by counsel
- Right not to be labeled for discriminatory reasons
- Right not to be institutionalized without reasonable cause
- Right to sue
- Right to hold contracts
- Right to treatment in the least restrictive alternative

Obligations of Society to Protect the Rights of All

- Right to obtain and refuse treatment
- Right to optimum developmental attainment
- Right to early interventive treatment
- Right to a family or surrogate family home
- Right to proper living conditions
- Right to physical access to all facilities
- Right to representation by an advocate
- Right to protection from harm

(Krishef, 1983, p. 171)

Table 2
EXECUTIVE LANDMARKS

- 1909 - White House Conference on the Care of Dependent Children (recognition of children's welfare is vital concern of nation)
- 1947 - The President's Committee on Employment of the (Physically) Handicapped (promoted employment of disabled veterans)
- 1961 - The President's Panel on Mental Retardation (recommendations on the subject of Mental Retardation)
- 1966 - The President's Committee on Mental Retardation PCMR's originated created a vital link between the White House and the administrative departments (federal and governmental; professional and volunteer)

Table 3

LEGISLATIVE LANDMARKS

- 1867 - The Office of Education (established the Department of Education)
 - Early in 1920's, a section on Exceptional Children and Youth was developed to document activities in education of handicapped children.
 - 1930 Elise Martens wrote Guide to Curricular Adjustments for the Mentally Disabled.
 - 1950 P.L. 815 & 874 allowed the Federal Government to provide construction and operating funds to local school districts
 - 1953 Office of Education studied personnel needs in special education with a grant from the Association for Crippled Children
- 1958 - National Defense Education Act
 - Title VII Education Media Research funding mental retardation projects
 - Federal Aid to Education
 - P.L. 85-926 for training educators of mentally retarded children (this was the first categorical legislation specifically devoted to mental retardation)
 - Title III of P.L. 88-164 funds for research and demonstration projects in education of handicapped
 - 1963 (P.L. 88-164) Division for Handicapped Children and Youth in the U.S. Office of Education (programs for the handicapped were elevated to a position in the OE administrative hierarchy)

- 1965 - Elementary and Secondary Educational Act (ESEA--
P.L. 89-10) Title I assistance to educationally
disadvantaged children
 - P.L. 89-313 assistance to handicapped children
in State operated private day and resident schools
- 1966 - Amendment of ESEA
- 1967 - Amendment of ESEA
- 1969 - Education of the Handicapped Act
(Title VI, P.L. 91-230)
 - Part A - development of education for mentally
retarded at mild and moderate levels
 - Part B - grants-in-aid to State agencies for
initiation, expansion, and improvement
of programs
 - Part C - (Sect. 621) regional resource centers
provisions for
(Sect. 623) Early Childhood Program
(Sect. 624) Education Instructional
Materials Centers
 - Part F - Instructional Media for the Handicapped
 - Part D - support of Special Education manpower
development
- 1974 - The Education Amendments
 - (P.L. 93-380) right to education
 - (P.L. 94-142) education programs adaptative to
native language
- 1912 - The Children's Bureau--a constituent agency of
Department of Labor looking at the plight of
children
 - 1919 - reviewed problems of mentally retarded
children
 - 1920 - Mental Clinic was established in Boston

- 1953 - incorporated into the Department of Health,
Education, & Welfare
- 1963 - University Affiliated Facilities constructed
- 1965 - Social Security Amendments,
Title V (Sect. 511) training of personnel
for care of crippled children, especially
mentally retarded children
- 1968 - Bureau dismantled,
Crippled children's programs went under Health
Services & Mental Health Administration
- 1920 - The Industrial Rehabilitation Act
retaining for disabled veterans of World War I
 - 1943 vehicle for the vocational habilitation of
mentally retarded persons
 - 1950 Vocational Rehabilitation of the Mentally
Retarded--a report on the training,
counseling, and placement of the mentally
retarded
 - 1953 strengthening support of services to the
retarded
 - 1954 amendment of the Act
 - 1965 Federal aid for construction and staffing
of workshops
 - 1968 amendments
 - 1974 liberalized eligibility restrictions
- 1935 - The Social Security Act--grants to the State to
support special health and welfare programs
(contributed the greatest volume of federal
dollars to mentally retarded children and adults)
 - 1957 disability provisions in Social Security and
public assistance programs

- 1969 President's Commission on Income Maintenance Programs
- 1974 aid to blind, aged, and disabled
- 1972 P.L. 92-603, Title XVI, provided Supplemental Security Income (SSI) for aged, blind, and disabled
- 1972 The State and Local Fiscal Assistance Act-- placed a ceiling of \$2.5 billion to State Social Services expenditures
- 1974 Title XX, consolidated Title IVA & VI
- 1975 SSI recipients are to receive State services
- 1965 - Title XIX, Federal sharing of medical care for public assistance recipients and medically indigents (Medicaid)
- 1971 - P.L. 92-223, institutions meeting certain standards eligible for intermediate Care Facility status made residents eligibility for Medicaid. (ICF/MR standards were developed by the Accreditation Council for Facilities for the Mentally Retardation
- 1957 - Amendment--A childhood disability beneficiary is an adult with a continuing disability acquired before age 22
- 1944 - Public Health Service Act (original act 1798) consolidated and revised all Federal activities of a public health nature and gave great boost to modern medicine
 - 1966 developed USPHS (United States Public Health Services)
 - 1946 The National Mental Health Act established the National Institute of Mental Health (NIMH)
 - 1967 reorganization of NIMH
 - 1962 National Institute of Child Health & Human Development

- 1963 Title I, Part A, constructions of the Mental Retardation Research Centers
- 1967 Bureau of State Service with a Division of Mental Retardation
- 1971 Division of Development Disabilities
- 1975 Hill-Burton Act replaced by P.L. 93-641, The National Health Planning & Resources Development Act

reorganization of Public Health Services
and Comprehensive Health Planning

1963 - Substantive Legislation in Mental Retardation

- P.L. 88-156 amended SSA comprehensive planning on a coordinated inagency basis
- grants for high risk mothers especially poverty areas
- P.L. 88-164 construction funds for research centers, university affiliated centers, community service facilities, and mentally health centers--training personnel for special education
- combined three separate pieces of legislation:
Title I, construction provisions and staffing
Title II, development of community mental health center
Title III, education bill--deal and special education training
- P.L. 89-333, broadened scope of sheltered workshops
- P.L. 89-10, mental retardation services to dependents of active duty military personnel

1970 - Developmental Disabilities Services & Facilities Construction Act (P.L. 91-517) new direction for mental retardation programs

- Developmental Disabilities Act. grant programs to assist states in range of services and operating support for programs
- 1972 Title I regulations
- 1975 - P.L. 94-103, Developmentally Disabled Assistance and Bill of Rights Act
 - grants for satellite center
 - funds for inappropriately placed persons
 - special projects grants
 - definition of developmental disability
 - comprehensive system for evaluation
- Title II detailed standards for institutions; basic rights of persons; habilitation

Table 4

MAJOR COURT CASES CONCERNED WITH THE RIGHTS OF
INSTITUTIONALIZED RETARDED PERSONS

- 1966 Rouse v. Cameron (District of Columbia)
Held that handicapped persons could not be confined solely because of a mental or physical disability. In addition, the court ruled that any involuntarily committed person had a right to treatment in order to regain his or her liberty.
- 1971 Wyatt v. Stickney (now Wyatt v. Aderholt) (Alabama)
Affirmed the constitutional right to treatment on behalf of persons confined to mental hospitals and institutions for the mentally retarded. The continuance of this case also led to a court ruling in 1973 upholding the right of a retarded person to have children and declaring the Alabama law on compulsory sterilization unconstitutional.
- 1972 New York Association for Retarded Children v. Rockefeller (now New York State Association for Retarded Children and Parisi v. Carey) (New York)
Centered on Willowbrook State School. Court action resulted in ruling that the residents had a right to freedom from harm. The order prevented the seclusion of residents in isolated rooms and required the immediate cessation of the use of arbitrary and unsupervised physical restraints, such as strait-jackets, or chemical restraints, such as certain types of drugs.
- 1972 Ricci v. Greenblatt (Massachusetts)
Decreed that the Massachusetts Institution for the Retarded at Belchertown had to assess the medical needs of its residents and provide a comprehensive treatment program.
- 1972 Jackson v. Indiana 406 U.S. 715 (1972)
Involved due process in commitment proceeding stated denied of equal protection to confine a handicapped person indefinitely until he should become competent.

- 1973 Souder v. Brennan 362 F. Supp. 808 (D.D.C. 1973)
Established the right to be free from institutional peonage and involuntary servitude.
- 1973 Urban League v. Washington Metropolitan Area Transit Authority (D.D.C. filed April 14, 1972)
Enforced the right of free access to buildings and transportation systems for mentally retarded persons and physically handicapped persons.
- 1974 Welsch v. Likins (now Welsch v. Dirkswager) (Minnesota)
Expanded the findings of the Wyatt court case by concluding that the state has a responsibility to develop and provide appropriate community services for the mentally retarded.
- 1974 Wyatt v. Aderholt 368 F. Supp. 1383 (M.D. Ala. 1973)
Upheld the right of mentally retarded persons to procreate and declared the Alabama compulsory sterilization law unconstitutional. Reversed the Supreme Court decision of 1927 which affirmed involuntary sterilization for eugenic reasons.
- 1975 Donaldson v. O'Connor (Florida)
Found that mental or physical handicaps alone are no justification for involuntary incarceration in a state institution. People who will do no harm to themselves or others, whether they are mentally ill, mentally retarded, physically unattractive, or otherwise socially unacceptable have a constitutional right to liberty and freedom--which means remaining in the community if they so choose.
- 1975 Horacek v. Exon (Nebraska)
Originally brought in 1972, challenging the poor conditions at the Beatrice State Developmental Center, an institution for the mentally retarded, and also challenging the inadequacy of community-based programs for retarded individuals. Voluntary agreement between state officials and plaintiffs was achieved. The case, however, was reopened in 1976, charging that the state had failed to live up to its agreements. Instead of the expansion of community programs, the exact opposite had occurred, with more community-

based residents entering Beatrice than Beatrice residents being placed into the community. The state legislature, in 1976, appropriated funds to be used in returning Beatrice residents to the community.

1977 Halderman v. Pennhurst (Pennsylvania)

Far-reaching court decision that held mentally retarded residents to have constitutional rights to habilitation that (1) takes place under the least possible restrictive conditions, (2) assures freedom from harm, and (3) offers equal protection of the law. The court finding was almost equivalent to forcing closure of Pennhurst because the judge concluded that Pennhurst, as an institution, should be regarded as a monumental example of unconstitutionality.

1978 Wuori v. Zitnay (Maine)

Judicial decision that decreed that persons released from an institution had the right to receive habilitation including medical treatment, education, training, and care suitable to meet their needs.

1981 Pennhurst State School v. Halderman; 1981; 1984

Litigation giving states more control by limiting the influence and control of the federal government. It delimited the least restrictive element of the federal government. It delimited the least restrictive element of the Developmental Disabilities Act as being merely a congressional preference for deinstitutionalization. The 1984 ruling basically invoked the 11th amendment in telling federal courts to avoid ruling on, or attempting to enforce state law matters regarding institutional services.

1982 Youngberg v. Romero

The right to safe conditions and freedom from undue bodily restraint, minimum standards via professional judgment that these rights have been safeguarded.

1984 Society for Goodwill to Retarded Children, Inc. v. Cuomo

The standard has been met if professional judgment is exercised in placing someone in an institution, or in continuing their services in that environment.

Table 5

MAJOR COURT CASES CONCERNED WITH RETARDED
PERSONS' RIGHTS TO PUBLIC SCHOOL EDUCATION

- 1954 Brown v. Topeka Board of Education (Kansas)
Concluded that separate educational systems did not provide for equal educational opportunities, and that all children were equally entitled to an education.
- 1967 Hobson v. Hansen (District of Columbia)
Declared that standardized group tests were unconstitutional because they discriminated against children from minority and economically deprived families.
- 1969 Wolf v. Legislature of the State of Utah (Utah)
Established the rights of trainable-level children to be educated in a state-supported public school system.
- 1970 Diana v. State Board of Education (California)
Declared that children had to be tested in their native tongue and could not be placed into special classes on the basis of culturally biased tests or tests that used a language different from the child's native speech.
- 1970 Spangler v. Board of Education (California)
Declared that standardized group intelligence tests were biased against black individuals and ordered that these tests could not be used as the determinant for placing a child into a special education class.
- 1972 Pennsylvania Association for Retarded Citizens v. The Commonwealth of Pennsylvania (Pennsylvania)
Declared that a free public education was the right of every retarded individual within the Commonwealth of Pennsylvania who was between the ages of six and twenty-one years.

- 1972 Mills v. Board of Education of the District of Columbia (District of Columbia)
Established the right of access to the public school system for every child, regardless of handicap. The court declared that lack of money could not be used as an excuse for failure to provide educational programs for handicapped children.
- 1972 Larry P. v. Riles (California)
Prohibited the placement of black children into special education classes based upon the criteria of I.Q. tests, which were considered to be culturally biased.
- 1972 Doe v. Board of School Directors of the City of Milwaukee (Wisconsin)
Ruled that public school systems could not refuse to furnish educational programs for certain children by placing the children's names on a waiting list for entrance "if and when a program became available".
- 1973 LeBanks v. Spears (Louisiana)
Ordered that education and training opportunities be made available to retarded persons over twenty-one years of age who had not been provided educational services as children.
- 1974 Michigan Association for Retarded Citizens v. State Board of Education of the State of Michigan (Michigan)
Found that the state public school system had failed to provide educational programs for residents of state institutions. The court ordered the public school system to provide these educational programs.
- 1974 In re G.H. (North Dakota)
The only decision by a state supreme court regarding equal educational opportunities for the handicapped child. The court held that a handicapped child was entitled to equal educational opportunity under the state constitution.

- 1974 Rainey v. Tennessee Department of Education (Tennessee)
Ordered swift implementation of state legislation providing for comprehensive special education, which had been passed by the state legislature but was moving very slowly. The court ordered that educational programs be provided for all handicapped children as soon as possible.
- 1977 Mattie T. v. Holliday (Mississippi)
Required the establishment of procedures for challenging evaluation/placement practices, prohibited the use of culturally biased tests, mandated adoption of mainstreaming approaches and use of a least restrictive setting, and called for setting up casefinding procedures.
- 1977 Connecticut Association for Retarded Citizens v. State Board of Education (Connecticut)
No ruling because of the passage of a state statute. The new law assured severely and profoundly retarded children the right to a free public school education.
- 1979 Armstrong v. Kline (Pennsylvania)
Established that retarded children have the right, if needed, to receive more education days per annum than are figured in the regular session.
- 1979 Casement v. Douglas County School District (Colorado)
Ruled that the same availability must exist in any school district for busing retarded children as for busing normal children.
- 1979 In re Jones (New York)
Ruled that if a retarded child attends a residential school during the summer, the cost of such schooling must be borne by public funds.

(Krishef, 1983, pp. 187-189)

Table 6

PUBLIC LAWS ENACTED BY THE U.S. CONGRESS
RELATING TO EDUCATION FOR THE
MENTALLY RETARDED

- | | |
|------|--|
| 1957 | <u>National Defense Education Act (Public Law 85-926)</u>
Made funds available to training those who would train teachers of the mentally retarded. |
| 1963 | <u>Mental Retardation Facilities Construction Act (Public Law 88-164 Part III)</u>
Designed to extend the provisions of Public Law 85-926 by providing for the training of special education personnel as well as the funding of demonstration projects in special education. |
| 1965 | <u>The Elementary and Secondary Education Act (Public Law 89-10)</u>
Provided funds for promoting programs to handicapped and culturally deprived children. |
| 1965 | <u>Amendments to Title I of the Elementary and Secondary Education Act (Public Law 89-313)</u>
Extended benefits of Public Law 89-10. Title I, to children who could be educated in facilities operated by agencies of the state, such as state institutions. |
| 1966 | <u>Amendments to the Elementary and Secondary Education Act (Public Law 89-750)</u>
Created the U.S. Department of Health, Education, and Welfare's Division of Education of the Handicapped, later to become the Bureau of Education for the Handicapped. |
| 1967 | <u>Education Professions Development Act (Public Law 90-35)</u>
Provided funds for the training of professionals concerned with education of the retarded. |

- 1968 Amendments to the Vocational Education Act
 (Public Law 90-576)
Required that 10% of all vocational education funds
to be used for training of the handicapped.
- 1969 Education Professions Development Act
 (Public Law 90-35)
Provided funds for the training of professionals
concerned with education of the retarded.
- 1969 The Learning Disabilities Act (Public Law 91-320)
Defined learning disabilities and made funds
available for the education of learning disabled
children.
- 1970 The Developmental Disabilities Services and
 Facilities Construction Act (Public Law 91-517)
Amended Public Law 88-164 and promoted a less
categorical approach than had previously been the
case with federal legislation. The law stressed
that the target population should be those who were
"developmentally disabled", defined as individuals
with mental retardation, cerebral palsy, epilepsy,
and other neurologically handicapping conditions.
- 1972 Amendments to the Economic Opportunity Act
 (Public Law 92-424)
Established requirements that handicapped children
were to make up 10% of those being served in Head
Start programs.
- 1973 Section 504 of the Rehabilitation Act
 (Public Law 93-112)
Prohibited discrimination on the basis of physical
or mental handicap in every federally assisted
program or activity. The law mandated the removal
of architectural barriers standing in the way of
educational opportunities for the handicapped and
also provided that employers could not refuse to
hire or promote a handicapped person solely because
of his or her disability.

1974 Education Amendments (Public Law 93-380)

Offered Congress's response to the Supreme Court decision regarding the "Right to Education". The law provided extension of previous legislation and assured protection of the rights of handicapped children with regard to decisions concerning their placements in educational programs.

1975 Education for All Handicapped Children's Act (Public Law 94-142)

Protected handicapped children by assuring them the rights to (1) placement in a least restrictive environment, (2) due process, (3) individualized educational plans, and (4) protection from erroneous classification. This landmark legislation mandated free, appropriate public school education for all handicapped children regardless of the severity of their handicap.

1978 The Rehabilitation Comprehensive Services and Developmental Disabilities Amendments (Public Law 95-602)

Promoted the idea of coordination, cooperation, integration, and unification of all federal programs and services dealing with the handicapped individuals. It changed the definition of developmental disability from the previous "categorical" approach to one that was more functionally based.

(Krishef, 1983, pp.182-183)

Findings

A review of 25 client charts for subjective comments in observation notes and nurses records revealed several patterns. The first being that in none of the records reviewed were there observation notes or records for the decade 1960. Twenty-three of the twenty-five charts chosen at random had admissions dated back to the 1960s. One rationale, as it was explained to this researcher, was that observation notes were not kept then. There was a dormitory log book on each unit and only unusual occurrences were logged. The location of those log books is currently unknown. Another rationale is that the nursing staff in the 1960s was strictly administrative and therefore no direct care occurred which necessitated nurses records. Record keeping was not a priority in the 1960s and many records were transferred with clients as they moved from school to school. Copies were not made, and some of the records were lost in the shuffle. It was explained that in the 1960s the need for accurate documentation was not identified or considered necessary.

The client charts from the 1970s revealed observation notes kept in a rote manner. The entries provide much the same information and explanations the same entries day after week after month. Such euphemisms as "whined", "sweet",

"good", "acted like a baby", "obnoxious", "no trouble", and "good mood" were recorded repeatedly in observation notes during the 1970s. The nurses records were found among the progress notes and in every case those rare entries were strictly short concise factual descriptions of a specific situation that had been brought to their attention. No element or evidence of subjectivity was noted in professional nurses entries. The nurses' comments were simply reflective of a specific problem and the attention or intervention provided responsive to medical orders.

The client records for the 1980s were more factual, simple statments of events as opposed to lengthy, flowery, detailed accounts of non-specific behaviors. The observation notes revealed only an occassional subjective comment, such as "well-behaved", "fine", "content", and "happy". The most frequently written subjective comment or cliché was "happy". The charting of events without subjective comments presented a more prepared context which suggested that the recorders had received some skills training in how to chart and document properly. Nurses records were again found in progress notes but the manner in which responsibility for clients needs was identified and more apparent. Nurses records were factual and

professional statements describing interventions taken as the results of physicians orders; but some degree of knowledge regarding additional problems that may need attention, or the awareness of others involved in the care of the client relative to specific situations and possible solutions were noted. The implications in this type of record keeping are that nurses are not only well prepared in the art of proper charting but also in implementation of the nursing process. The process of thinking ahead, planning one's intervention, evaluating that intervention effectiveness, awareness of possible divergence in the progress of the client, replanning possible interventions and re-evaluating the best course of action or intervention were apparent in professional nurses records reviewed in the 1980s.

One can accurately state that in progressive years a better understanding of the purpose of observation notes and nurses records improved to a point that the factual statements of events is recorded in a prepared manner and that professional nurses were implementing the nursing process. The chief of nursing service at the state school where an interview took place supported previous findings by stating that the nurse is now a professional incorporating all the advantages of her educational background. She

also stated the belief that nurses are utilizing the nursing process by identifying areas of needs, establishing objectives and providing purposeful interventions, all directed at providing the best care possible for the client.

Professional nursing has moved from an administrative or figure-head role, to a supervisory role, working with direct care providers to become involve in every aspect of the direct care. A role of purposeful intervention has emerged, monitoring the client's entire program as it relates to other disciplines. The role of the professional nurse is vital as a part of the interdisciplinary or multidisciplinary team. The professional nurses' knowledge of the client as a whole individual interacting within his environment and awareness of how his programming affects him helps the nurse to make informed, valued decisions. Professional nursing is becoming a discipline within itself moving away from the nurse bound singly to the medical model. Physicians are viewing the nurse as a responsible and necessary part of total patient care in their interventions with persons who are mentally retarded. Nurses are implementing more programs and inservice education programs for themselves as well as for staff directly involved in the care of clients. The role of the professional nurse in the institutional setting as well as in the community

setting is demanding in various areas other than medicine, thereby making the area of nursing as multi-faceted as the educational background in which training has been received.

Conclusions

Various accounts regarding the care and treatment afforded people who are mentally retarded must provide an alert to the atrocities and cruelties mankind has heaped upon its brothers. The main conclusion one can reach as a result of this historical look at the field of mental retardation is that it did indeed occur as reported in the many sources and references available. It was not a bad nightmare from which one can just awaken, it happened. There was no one person, place, or thing to blame, and individual responsibility cannot be established. Society as a whole allowed it to happen and society as a whole must accept responsibility and guarantee that every human being has the right to be treated like a human being. Society must emerge from its cocoon of self-interest and indifference if true eradication of discrimination is to occur and total acceptance and integration to emerge. Society must denounce the evils that men do to each other if it is to truly call itself civilized.

Implications for Future Study

This study has implication for nursing practice in that many nursing students are graduating from their respective schools with little or no true understanding of the varied opportunities in the field of mental retardation. In order to understand these opportunities, one must have a historical understanding of where mentally retarded persons have been and the long struggle out of the darkness and into the present day world. Curriculum tracing the historical aspects of mental retardation and training in service delivery would prepare nurses to actively engage this area with true professionalism. Understanding community services and delivery of those services would aid in seeking knowledge for specific persons with mental retardation. A study comparing nurses in the field of mental retardation with nurses in the traditional setting would help bridge a gap between the two specialty areas. A study of school nurses and how they are helping school systems deal with educating the handicapped would reveal areas of possible need within the school system. Studies of children kept at home with full exposure to community services compared to clients that were institutionalized would be beneficial. Additional topics include: a study on current societal attitudes

towards mentally retarded individuals; a study on community adjustment and how nursing can help in the adjustment process; preparedness of clients as they are deinstitutionalized into the community, and how prepared the community really is for these individuals; where is government going with funding for social programs that effect mentally retarded persons especially in these days of budget override and cuts.

In the end,

Artisits should be judged by their best works,
Individuals by their finest hours,
And societies by their worst behavior.

Burton Blatt

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INTERVIEWS

INTERVIEWS

1. Interview with the parent of a child who is mentally retarded.
2. Interview with an employee monitoring program plans.
3. Interview with a registered therapist.
4. Interview with administrative nursing professional.
5. Interview with direct care nursing professional.
6. Interview with community return professional.
7. Interview with community placement professional.
8. Interview with community services nursing professional.
9. Interview with community services administrative nursing professional.
10. Interview with direct care attendant.

APPENDIXES

APPENDIX A

Research Review Committee Form

SEP 24 1986

TEXAS WOMAN'S UNIVERSITY
Box 22939, TWU Station
RESEARCH AND GRANTS ADMINISTRATION
DENTON, TEXAS 76204

HUMAN SUBJECTS REVIEW COMMITTEE

Name of Investigator: Eleanor Woods Center: Denton
Address: Rt. 1 Box 37-A Date: 9-23-86
Pilot Point, Texas 76258

Dear Ms. Woods

Your study entitled Selected Variables Influencing the Care
and Treatment of the Mentally Retarded: 1960-1985.

has been reviewed by a committee of the Human Subjects Review
Committee and it appears to meet our requirements in regard
to protection of the individual's rights.

Please be reminded that both the University and the Department of Health, Education, and Welfare regulations typically require that signatures indicating informed consent be obtained from all human subjects in your studies. These are to be filed with the Human Subjects Review Committee. Any exception to this requirement is noted below. Furthermore, according to DHEW regulations, another review by the Committee is required if your project changes.

Any special provisions pertaining to your study are noted below:

 Add to informed consent form: No medical service or compensation is provided to subjects by the University as a result of injury from participation in research.

 Add to informed consent form: I UNDERSTAND THAT THE RETURN OF MY QUESTIONNAIRE CONSTITUTES MY INFORMED CONSENT TO ACT AS A SUBJECT IN THIS RESEARCH.

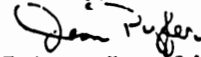
 The filing of signatures of subjects with the Human Subjects Review Committee is not required.

 Other:

XX No special provisions apply.

cc: Graduate School
Project Director
Director of School or
Chairman of Department

Sincerely,



Chairman, Human Subjects
Review Committee

at Denton

9/10/82

APPENDIX B

Approval Letter from Graduate School



Texas Woman's University

P.O. Box 22479, Denton, Texas 76204 (817) 898-3400, Metro 434-1757, Tex-An 341-3400

THE GRADUATE SCHOOL

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October 27, 1986

Ms. Eleanor Woods
Rt. 1 Box 37-A
Pilot Point, TX 76258

Dear Ms. Woods:

I have received and approved the Prospectus for your research project. Best wishes to you in the research and writing of your project.

Sincerely,

A handwritten signature in cursive script that reads 'Leslie M. Thompson'.

Leslie M. Thompson
Provost

cc: Dr. Anne Gudmundsen

APPENDIX C

Agency Permission Form

TEXAS WOMAN'S UNIVERSITY
COLLEGE OF NURSING

AGENCY PERMISSION FOR CONDUCTING STUDY*

THE Denton State School Medical Director } Chairman
 } of Research
 } Committee

GRANTS TO Eleanor L. Woods RN
a student enrolled in a program of nursing leading to a
Master's Degree at Texas Woman's University, the privilege
of its facilities in order to study the following problem.

The care & treatment of Mentally Retarded
Individuals 1950 - 1985. A focus on the
role of the nurse then & the role of the
nurse now.

The conditions mutually agreed upon are as follows:

1. The agency (~~may~~) (may not) be identified in the final report.
2. The names of consultative or administrative personnel in the agency (~~may~~) (may not) be identified in the final report.
3. The agency (~~wants~~) (does not want) a conference with the student when the report is completed.
4. The agency is (willing) (~~unwilling~~) to allow the completed report to be circulated through interlibrary loan.
5. Other _____

Date: 9-24-86

[Signature]
Signature of Agency Personnel

Eleanor L. Woods
Signature of Student

[Signature]
Signature of Faculty Advisor

*Fill out & sign three copies to be distributed as follows:
Original - Student; First copy - Agency; Second copy - TWU
College of Nursing.

APPENDIX D

Letter



Gary E. Miller, M.D.
Commissioner

Texas Department of Mental Health and Mental Retardation

Central Office

P.O. Box 12668 • Austin, TX 78711-2668 • (512) 454-3761

178

February 21, 1986

Ms. Eleanor Woods
Route 1, Box 37-A
Pilot Point, Texas 76258

Dear Ms. Woods:

Enclosed is the information as we discussed in our telephone conversation of February 19, 1986. Please contact me if you have additional questions.

Sincerely,

Calessa Vinson
ICF-MR Program Coordinator

CV/dt
Enclosures

cc: Rosalie Garcia, ICF-MR Program Coordinator
Darlene Kimbley, ICF-MR Program Coordinator

APPENDIX E
Implications for Nursing

IMPLICATIONS FOR NURSING

Since 1912 the federal government has expressed a sustained national interest in children who are handicapped or who are vulnerable to handicapping or crippling conditions. Notable changes in emphasis can be identified through a study of the legislative history in this area. The following are a few examples of changes that have influenced nursing practice.

<u>From</u>	<u>To</u>
Treatment	Prevention and early case-finding
Treatment of most obvious single conditions	Treatment of less obvious and multiple conditions
Focus on individual	Focus on individual in the context of his family and other social institutions
Services for special population groups such as poor or rural	Services for all on a statewide or regionalized basis
Reduction of mortality	Reduction of morbidity and improved quality of life
Crisis or episodic care	Ongoing services for health maintenance
Physically oriented medical care	Multidisciplinary comprehensive health care
Inpatient hospital care	Ambulatory and increased emphasis on primary care
Professional accountability	Public accountability

(Norris, 1975, p. 316)

APPENDIX F

Legal Rights of the Mentally Retarded
Guaranteed by the Texas Mentally
Retarded Person's Act of 1977

LEGAL RIGHTS OF THE MENTALLY RETARDED GUARANTEED
BY THE TEXAS MENTALLY RETARDED PERSON'S ACT OF 1977

I. Basic Bill of Rights for All Mentally Retarded Citizens

1. Rights guaranteed under the Constitutions and the laws of the United States and the State of Texas.
2. Right to protection from exploitation and abuse
3. Right to least restrictive living environment
4. Right to education
5. Right to equal opportunities in employment
6. Right to equal housing opportunities
7. Right to treatment and habilitative services
8. Right to comprehensive diagnosis and evaluation; right to an additional independent diagnosis and evaluation; right to contest the results of the diagnosis and evaluation in an administrative hearing
9. Right to presumption of competency
10. Right to due process in guardianship proceedings
11. Right to fair compensation for labor

II. Additional Rights of Clients Receiving Mental Retardation Services from the Texas Department of Mental Health-Mental Retardation and from Community Mental Health-Mental Retardation Centers

1. Right to least restrictive alternative
2. Right to individualized alternative
3. Right to periodic review of habilitation plan and to a periodic comprehensive rediagnosis and re-evaluation
4. Right to be informed of progress and to participate in planning

5. Right to withdraw from voluntary mental retardation services
6. Right to be free from mistreatment, neglect and abuse
7. Right to be free from unnecessary and excessive medication
8. Right to submit grievances to the public responsibility committee
9. Right to be informed of rights on admission for mental retardation services

III. Additional Rights of Residents in a Residential Care Facility

Residents have all of the rights listed above, and because they are living in a 24-hour residential facility, they also have the following rights:

1. Right to prompt and adequate medical and dental care and treatment
2. Right to a normalized residential environment
3. Right to a humane physical environment
4. Right to communication and visits
5. Right to personal property

APPENDIX G

Sunset Commission

PROPOSED AREAS OF FOCUS
Texas Department of Mental Health and Mental Retardation
 June 11, 1986

OVERALL ADMINISTRATION

1. Develop an organizational structure that is more responsive to the needs of clients/patients and to the needs of the various components of the system.

Examples: Determine where communication could be improved by clarifying lines of authority and ensuring appropriate span of control.

Evaluate the impact on the agency's management of the Director of Operations position.

Determine if there is a need for naming the various deputy commissioners and stating their qualifications in statute.

2. Improve public confidence in the MHMR system by increasing accountability.

Examples: Examine how internal audit and quality assurance reports are used to improve services.

Determine if the department has an appropriate system for monitoring collections in each facility.

Assess the level of accountability provided by the current contracting system and how this could be improved.

3. Eliminate monitoring that is duplicative or unnecessary to ensure that state dollars are being spent appropriately.

Examples: Evaluate the appropriateness of the department monitoring community center's programs that are not state-funded.

Determine if the use of interagency contracts could reduce the number of programmatic and fiscal audits of programs receiving funds from multiple state sources.

Examine the need for ICF-MR facilities to meet state licensing standards for nursing homes.

4. Improve the funding mechanism so better use is made of the agency's limited resources.

Examples: Examine possible ways to increase federal funding, such as Medicaid for mental health services.

Determine whether the agency's fee system is collecting an appropriate portion of total costs.

Evaluate the agency's method of allocating funds to community programs to determine whether it is equitable and provides proper incentives.

Examine the institutional needs of the agency to determine whether a plan should be developed for closing facilities.

EVALUATION OF MAJOR ISSUES

5. Clarify the state's responsibility for serving mentally ill and mentally retarded individuals.

Examples: Evaluate the appropriateness of statutorily prioritizing services and/or recipients of services.

Determine if the requirement for "legally adequate consent" unnecessarily impedes a mentally retarded person from getting services.

6. Eliminate gaps in services and/or duplication of services when multiple agencies are serving similar populations.

Examples: Determine if one agency should be responsible for all substance abuse programs.

Clarify in statute where the primary responsibility for serving mentally ill and mentally retarded offenders should be.

Examine the benefits of consolidating state-supported genetics programs.

7. Strengthen the department's efforts to provide a balanced array of services based on (a) the needs of mentally ill and mentally retarded Texans and (b) the financial capacity of the system.

Examples: Determine if adjustments are needed in the \$35.50 and \$55.60 programs to ensure that (a) needed community services are available, (b) the dollars are following the client, and (c) state funds are expended in the most cost-effective manner.

Establish mechanisms that will enhance the use of state and community facilities as the client population shifts.

Examine the pros and cons of the single portal of entry concept.

Determine the department's role in enhancing the development of quality community-based services.

8. Improve the use of federal Medicaid dollars for services for mentally retarded individuals.

Examples: Determine if TDMHMR should have control over Medicaid funds used for community-based services for mentally retarded persons.

Determine what changes are needed to encourage private sector involvement in the provision of ICF-MR services.

Establish reasonable guidelines for the closure of privately operated ICF-MR facilities.

APPENDIX H

Lelsz v. Kavanagh
Court Case

IN THE UNITED STATES DISTRICT COURT
FOR THE EASTERN DISTRICT OF TEXAS
SHERMAN DIVISION

JOHN LELSZ, et. al., individually and on
behalf of all others similarly situated,

Plaintiffs

v.

JOHN J. KAVANAGH, M.D., et. al.,

Defendants

CIVIL ACTION
NO. S-74-95-CA

RESOLUTION AND SETTLEMENT

1. The Basis For This Resolution and Settlement

1. The people of the State of Texas have a vital interest in helping people with retardation fulfill their potential as individuals and as contributors to society. People with retardation are, first and foremost, people with a capacity to learn, develop and improve their ability to relate to and enrich the environment in which they live. The characteristics of retardation--a varying composite of less than age-expected intellectual or social development--make it necessary for them and their families to receive a variety of individualized services to minimize the adverse effect of retardation on personal and social growth and to enhance the achievement of each person's potential. The people of the State, through Acts of the Legislature and through the Texas Department of Mental Health and Mental Retardation (hereafter Department), and in accord with federal law, endeavor to provide such individualized services through a broad range of facility and community-based programs. It is recognized that

the goals of these services are best achieved in environments that approximate to the greatest possible extent those in which non-retarded people spend their lives, for example, ordinary homes and work places.

2. All parties to this action desire that this Resolution and Settlement will benefit the members of the plaintiff class and will assist those responsible for provision of services to people with retardation to maintain consistently high and legally sufficient standards. The entry of this Resolution and Settlement should not be construed as an admission by the defendants of liability nor does it constitute an admission of the truth of any of the allegations contained in the complaints filed in this cause. There is substantial agreement among the parties that positive changes have occurred during the pendency of this lawsuit. The defendants contend that the provisions in this Resolution and Settlement represent, in large part, ongoing programs which have already been initiated by the defendants. The parties believe that the entry of this Resolution and Settlement will serve the interests of the plaintiffs and defendants by providing for the continuation of the recognition and protection of the rights of plaintiff class members.

3. The provisions herein are intended to permanently secure the right to safety and protection from harm for members of the plaintiff class under the Fourteenth Amendment to the United States Constitution. These provisions are also intended to secure plaintiffs' other constitutional rights, their rights under

federal statutes and their rights under state law, including the Texas Mentally Retarded Persons Act.

4. Jurisdiction is conferred on this Court by 28 U.S.C. 1331 and 1343(3) and (4). This action for declaratory and injunctive relief is authorized by 42 U.S.C. 1983 and 1988, the United States Constitution, 28 U.S.C. 2201 and 2202, and Rule 57 of the Federal Rules of Civil Procedure. This Court has jurisdiction of the subject matter of this action and of all parties in the case. The Court has the authority to approve and implement the relief in this Resolution and Settlement and any plans pursuant thereto.

5. These provisions include a final resolution of the defendants' obligations towards the members of the plaintiff class and of the issues raised by this litigation. To the extent that current information renders final settlement of an issue impracticable, the parties have agreed upon a schedule and process for planning, negotiation and further judicial action which the parties believe will lead to a final resolution of the issue in a fair and reasonable manner. The plaintiffs and defendants agree that the defendants should have a reasonable time to develop plans and that the parties should have a reasonable time to attempt to reach agreement on such plans, thus avoiding, if possible, judicial action. This process will allow the plaintiffs ample opportunity to comment at significant points during the defendants' planning process so that the needs of the class will be served.

6. a. The members of the plaintiff class are all persons (a) who are or in the future are residents of the Austin State School, Denton State School or Fort Worth State School, (b) who have been residents of any of these three state schools since November 27, 1974, or (c) who are listed on the defendants' Registry for State School Placement either as of the filing of the Registry with the Court or at any time thereafter. Due to the length of this litigation, it is understood that not all former residents of Austin, Denton, and Fort Worth State Schools can be identified and located by the defendants; many have moved to other states, are deceased or have been assimilated into the mainstream of society.

b. This Resolution and Settlement applies to residents who currently or in the future reside in, or who will after the execution of this Resolution and Settlement have resided in, Austin State School, Denton State School, and Fort Worth State School or any facility operated by the three state schools and to those other members of the plaintiff class who come forward and request services. It is understood by the parties that defendants will provide the services in the Resolution and Settlement to those members of the plaintiff class described in this paragraph who currently or in the future are residents of any of the defendants' facilities. While the Department is a funding source for community centers through the grant-in-aid process and for local agencies through contracts, it is understood by the parties that defendants are not obligated to pay for services to the specific plaintiff class members as described above in this paragraph who are not residents of defendants' facilities. This provision is not intended to preclude coordinating mechanisms between state

facilities and community centers to permit reallocation of resources based upon identified shifts in service delivery responsibilities.

II. Obligations of Defendants

7. The defendants will provide to each member of the plaintiff class habilitation tailored to the person's individual needs. In meeting the habilitation needs of members of the plaintiff class, the individual's particular circumstances, including age, degree of retardation and handicapping conditions, will be taken into account. Habilitation is that education, training and care required by each plaintiff class member to improve and develop the person's level of social and intellectual functioning, designed to maximize skills and development and to enhance ability to cope with the environment, and provided in the setting which is least restrictive of the person's liberty. Defendants will provide habilitation services necessary to meet the needs of plaintiff class members until such time as they no longer require services under this Resolution and Settlement.

8. Defendants will provide each member of the plaintiff class with the least restrictive alternative living conditions possible consistent with the person's particular circumstances, including age, degree of retardation and handicapping conditions. Consistent with the person's capacities, each member of the plaintiff class will be taught adequate skills to help the person progress within the environment and to live as independently as possible. Services will be offered with utmost regard for the class member's dignity and personal autonomy.

9. The defendants will use their best efforts to overcome all obstacles and barriers to the creation of facilities and programs for habilitation outside the institution as required by this Resolution and Settlement.

10. Defendants will provide accessible, quality medical and dental services for each plaintiff class member. All such care shall be consistent with generally accepted professional standards in the community as applied to other citizens and shall be performed by, or under appropriate supervision of, licensed physicians and dentists.

11. (a) Defendants will take appropriate precautions to prevent the physical or psychological abuse or neglect of each plaintiff class member.

(b) Client abuse is divided into three categories:

(1) Class I abuse is defined as any act or failure to act done knowingly, recklessly or intentionally, including incitement to act, which caused or may have caused serious physical injury to a client;

(2) Class II abuse is defined as any act or failure to act knowingly, recklessly or intentionally, including incitement to act, which caused or may have caused non-serious physical injury to a client;

(3) Class III abuse is defined as any verbal or other common action, to curse, vilify or degrade a client, or threaten a client with physical or emotional harm, or any act which vilifies, degrades, or threatens a client with physical or emotional harm.

(c) Client neglect is defined as the negligence of any employee which causes any physical or emotional injury to any client.

(d) Each alleged incident of abuse or neglect shall promptly be investigated. Acts of abuse or neglect against plaintiff class members are proscribed and will result in disciplinary action which may include dismissal against those persons found to be responsible.

(e) Defendants will report to the resident involved and that person's parent, if a minor, or guardian as to the outcome of the allegation of abuse. Such report will describe the allegation of abuse, state whether abuse was confirmed, and report the results of any disciplinary action, when taken. This report need not include the identities of employees or other clients.

(f) Allegations of serious, willful, physical abuse will be reported to local law enforcement authorities.

12. Defendants shall ensure that no plaintiff class member is denied, or restricted from participation in, any program or service in the individual service plan for the purpose of punishment or discipline. This paragraph is not intended to restrict legitimate elements of a behavior modification program adopted and monitored by the interdisciplinary team through the individual service planning process.

13. (a) Defendants will provide a written individual service plan formulated in accordance with professional standards for each member of the plaintiff class, provide review thereof at least annually, and provide for the participation in the development of the individual service plan by each member of the plaintiff class consistent with the person's capacities. Consistent with this Resolution and Settlement, the individual service planning process will be directed toward

maximum personal and social growth and development, including a residential environment which is as much as possible like that of persons who are not retarded.

(b) The parents of a minor class member, or the guardian of the person of a class member, will be given the opportunity to participate in the development of the individual service plan. The individual service plan will be developed by an interdisciplinary team which is appropriately constituted in accordance with professionally acceptable standards and which includes the person or persons primarily responsible for the daily care and support of each plaintiff class member. Notification of individual service plan meetings regarding development of individual service plans or major modifications of such plans will be provided as far in advance as practicable and, for annual staffings, should be provided at least two weeks prior to the meeting.

(c) The individual service plan will be based on an evaluation of the actual needs of the plaintiff class member even if the needed facilities, programs or services are not currently available. When the facility, program or service needed by a plaintiff class member is currently unavailable, the individual service plan will contain a clearly identified interim program based on available services and resources which will meet, as nearly as possible, the actual needs of the person. The number and characteristics of plaintiff class members in need of a facility, program or service which is not currently available and the nature of the needed facilities, services and programs will be annually compiled by the defendants and made available to the plaintiffs; defendants will use this information in future planning. The process under this paragraph is not intended to limit flexibility in adjusting individual service

plans, through the interdisciplinary team process, as the needs of plaintiff class members change.

14. The defendants will monitor and regulate the prescription and administration of medication to ensure its appropriate and effective use and to avoid its unnecessary, excessive, or improper use. Medication shall not be used as punishment or as a substitute for habilitation. An habilitation program may include medication as an element.

15. Defendants will recruit qualified personnel to provide quality mental retardation services to plaintiff class members. Defendants will make appropriate efforts to screen out those applicants for employment who might pose a danger to clients. Defendants will require staff orientation and training programs to increase the employees' skills and interests in achieving the goals of each plaintiff class member as set forth in that person's individual service plan and to increase the employees' understanding of the terms of this Resolution and Settlement. Defendants will make appropriate efforts to ensure that employees are sensitive to the needs and rights of plaintiff class members, including those set forth in this Resolution and Settlement. For those persons already involved in providing services to members of the plaintiff class, training will be provided within one year of the date of final district court approval of this Resolution and Settlement. Defendants will keep records of all employees receiving training and such records will be available to plaintiffs through their counsel. Defendants will make appropriate efforts to ensure that all employees involved in

providing services to members of the plaintiff class receive the required orientation and training prior to beginning work at the assigned work station.

16. Defendants will, through program standards, regulations and evaluation mechanisms to be established by the Department, ensure that facilities, programs, and services to members of the plaintiff class operated directly or through contracts or grants-in-aid provide appropriate services consistent with this Resolution and Settlement.

17. A variety of residences can be used or adapted for each plaintiff class member regardless of degree of disability. The level of retardation and degree of disability of a member of the plaintiff class is not, in and of itself, a barrier to appropriate community placement.

18. Defendants will protect plaintiffs' existing rights to communicate with other persons, organizations and authorities by mail, telephone, visits and other means, including auxiliary communication aids for people with handicaps, and to possess and use personal property.

19. No member of the plaintiff class shall be relocated from an institution to any non-institutional residential program unless such program will offer the individual a better opportunity for personal development and a more suitable living environment.

20. Defendants will provide appropriate discharge planning through the individual service plan process for plaintiff class members who are to be discharged or furloughed from the institution. Through assignment of a case manager to each such plaintiff class member, the defendants will ensure appropriate links between institutions and non-institutional facilities, programs and services.

21. The defendants will provide to members of the plaintiff class an administrative forum for the resolution of individual problems, if such problems cannot be resolved informally. Members of the plaintiff class will have access to assistance from the staff of the Client Services and Rights Protection division in the Department's Central Office. The staff of this division is directed by the Commissioner to make appropriate efforts to resolve complaints from a plaintiff class member. Resolution of such complaints will include access to a Department appeal process. The Department plan under paragraph 25 below will include a statement of appealable issues and the standards applicable to the hearing process. In addition to the internal rights protection mechanisms established by the Department's Office of Client Services and Rights Protection, defendants will endeavor to utilize other appropriate programs and services, internal and external to the Department, to assist in protecting the rights of plaintiff class members and to advocate on their behalf for needed services.

22. Defendants will take appropriate precautions to keep every building which houses plaintiff class members safe, clean, free of bad odors, comfortably temperature-controlled and insect-free.

23. Standards for Austin State School, Denton State School and Fort Worth State School will be developed by defendants; a plan for such standards and their implementation will be filed by defendants on or before December 31, 1983.

24. Standards for community residential facilities will be developed by defendants; a plan for such standards and their implementation will be filed by defendants on or before December 31, 1984.

III. Management, Planning and Reporting

25. Defendants will prepare a plan encompassing the provisions of this Resolution and Settlement within the context of a statewide planning process for retardation services and, upon completion, will submit said plan to plaintiffs for comment. Following a reasonable time for comment by plaintiffs, the defendants' plan will be submitted to the expert consultant for review. Such a comprehensive plan will be completed by December 31, 1984. The completion date may be extended for good cause.

26. Defendants will report to the Court on a quarterly basis the progress of the development of the plan under paragraph 25 and will, upon completion of the plan, continue to file such reports regarding implementation of the plan.

27. Defendants will report to the Court on a quarterly basis the status of implementation and activities related thereto.

28. Defendants will take all action necessary to secure full implementation of this Resolution and Settlement, including coordinating with other agencies and officials of the State of Texas and delegating among themselves and their subordinates appropriate and specific responsibilities.

29. Subject to paragraph 30, defendants will use any flexibility granted by the Texas Legislature to facilitate compliance with this Resolution and Settlement.

30. The provision of services under this Resolution and Settlement will not reduce services received by any person, whether or not a member of the plaintiff class.

31. Defendants shall in their normal budgeting process or as needed prepare and present to the Legislative Budget Board, the Governor, the Legislature and all other appropriate entities, including departments and agencies of the United States, budgets, proposals, applications, requests and documentation for all necessary and appropriate funding, approvals, assistance, waivers, support and changes in law, regulations and practices, relevant to comprehensive implementation of this Resolution and Settlement. The parties recognize that the Texas Legislature is not bound by this Resolution and Settlement to appropriate funds.

32. The defendants, through collaboration with the Texas Department of Human Resources, will seek the Home and Community Based Services Waiver under the provision of 1915(c) of the Social Security Act in order to maximize funds

available for home and community based services for persons with retardation under this Resolution and Settlement.

IV. Monitoring and Enforcement

33. On or before September 1, 1986, the parties agree to seek a resolution of any outstanding relevant issues. If the parties cannot agree on a resolution of these issues, they will report to the Court by December 31, 1986 and the Court will resolve said issues. This paragraph is intended to provide a convenient procedure to address implementation issues which may arise after the defendants' plans are filed; it is not to be construed to affect or delay any of defendants' obligations, to excuse any noncompliance with these provisions or to waive plaintiffs' rights to seek enforcement or other remedies at any time.

34. Defendants will report to the Court on a quarterly basis regarding client movement data, including but not limited to the number of admissions, deaths, community placements, and estimates of these data for the next quarter.

35. The parties will agree on formats for the reports required by this Resolution and Settlement at paragraphs 26, 27 and 34.

36. (a) The plaintiffs and defendants request the Court to appoint an expert consultant to serve as monitor of implementation of this and any further orders of the Court.

(b) The parties will attempt to agree on an appropriate person for appointment. If no agreement is reached, the Court will select the expert

consultant after consideration of nominations by the parties. If the position becomes vacant, the same appointment process will be followed.

(c) The expert consultant will begin work not sooner than four months following appointment, unless the parties agree to an earlier or later date.

(d) The expert consultant will not supervise or direct the defendants or their employees and will not manage or operate any service or facility.

(e) The expert consultant will monitor implementation at least semi-annually and will submit at least annually reports to the Court.

(f) The expert consultant may, at any time, make recommendations concerning the implementation of this Resolution and Settlement to the defendants, with copies of such recommendations to the plaintiffs. Defendants will have thirty (30) days from receipt of a recommendation to accept, reject or propose alternatives to such recommendation, with copies of the response to the plaintiffs. If, within thirty (30) days of the receipt of defendants' response by the expert consultant and the plaintiffs, the defendants, plaintiffs and expert consultant are unable to reach agreement on a recommendation, any one of the three may ask the Court to resolve the issue. If the defendants, plaintiffs and expert consultant reach agreement on a recommendation, the recommendation will be filed with the Court by the expert consultant within thirty (30) days of agreement and will become part of this Resolution and Settlement.

(g) The expert consultant will be allowed access to all information, records, residential environments, programs and service areas, except attorney-client communications and defendants' self-evaluation surveys in connection with licensure, certification, and internal quality assurance reviews and program audits, and will be permitted to interview any persons affected by or

involved in the implementation of this Resolution and Settlement to the extent necessary to discharge the consultant's duties under this Resolution and Settlement.

(h) The term of the expert consultant will be five (5) years from the consultant's initiation of activities. The expert consultant will perform the duties above part-time, periodically and as necessary. The defendants will pay into the Registry of the Court \$215,000 for the use of the expert consultant. From this fund, the expert consultant may withdraw from the Registry upon order of the Court no more than the sums indicated:

Sept. 1, 1983 - Aug. 31, 1984	\$40,000	plus interest earned	
Sept. 1, 1984 - Aug. 31, 1985	\$40,000	plus interest earned	plus
		unexpended balance from the	
		previous year	
Sept. 1, 1985 - Aug. 31, 1986	\$45,000	plus interest earned	plus
		unexpended balances from the	
		previous years	
Sept. 1, 1986 - Aug. 31, 1987	\$45,000	plus interest earned	plus
		unexpended balances from the	
		previous years	
Sept. 1, 1987 - Aug. 31, 1988	\$45,000	plus interest earned	plus
		unexpended balances from the	
		previous years	

At the end of the term of the consultant, any unexpended funds plus interest earned shall be returned by the Registry of the Court to the State of Texas.

(i) Prior to beginning duties the expert consultant will prepare and submit to the Court for approval a proposed budget and description of proposed activities, including access under 35(g) above and the cost of any staff or consultants. Thirty (30) days prior to the submission of the proposed budget to the Court, the expert consultant will submit it to the parties for their comments. Each year thereafter, within thirty (30) days of the anniversary date of the initiation of the expert consultant's term, the expert consultant will

submit, for comment by the parties, a proposed annual budget to the Court for approval. The expenses of the expert consultant shall be borne by the defendants as costs of litigation.

(j) Said term will not be extended by the Court unless plaintiffs demonstrate that substantial compliance with this Resolution and Settlement has not been achieved. If defendants demonstrate that substantial compliance has been achieved prior to the expiration of the term, the Court shall shorten the term.

V. Notice

37. Each defendant and each employee known to be providing direct services to plaintiff class members shall be provided a copy of this Resolution and Settlement. A notice shall be posted at all times in all administrative offices notifying employees of their obligation to retain a copy of and to maintain knowledge of their obligations under this Resolution and Settlement. The parties shall agree on the form of notice.

38. Defendants will make a reasonable number of copies of this Resolution and Settlement available on request to concerned individuals, local agencies, advocacy and consumer groups.

39. Defendants shall prepare and publish a summary of the provisions of this Resolution and Settlement in clear and easily understood language and in a format, including graphics, which will be utilized in a program of educating members of the plaintiff class in their rights under this Resolution and Settlement; alternative means for such education shall be devised for class members with sensory or severe handicapping conditions.

40. This Resolution and Settlement shall be binding on the defendants and their officers, employees, agents, successors and all persons acting in concert with them.

41. Plaintiffs' counsel may apply to the Court for appropriate relief on matters of significant concern to the class.

42. Jurisdiction is retained by the Court until further order, to enable any party to apply at any time for such orders as may be necessary or appropriate for the interpretation, implementation, enforcement or modification of the terms of this Resolution and Settlement, including the activities and funding of the expert consultant, and for supervision, approval, resolution and further orders regarding issues left for further planning and negotiations.

43. The parties agree that six months after the end of the consultant's term they will attempt to reach agreement on the nature and extent of the need, if any, for continuing jurisdiction of the Court. If the parties are unable to reach agreement, the matter will be resolved by the Court.

VI. Approval of Resolution and Settlement and Notice to Members of the Plaintiff Class

44. Plaintiffs and defendants will cooperate in the submission of this Resolution and Settlement to the Court promptly and will recommend acceptance of this Resolution and Settlement to all necessary persons. All parties will take steps that may be requested by the Court and will otherwise use their respective best

efforts to consummate this Resolution and Settlement and obtain entry of a final order approving the Resolution and Settlement. Defendants shall be responsible for providing notice. All members of the plaintiff class and their parents or guardians shall receive notice of this Resolution and Settlement in the following manner:

(a) Defendants will prominently post in each administration building and in each building of an institution in which retarded clients are served and will send to each program or service for members of the plaintiff class held outside the institution the attached notice of this Resolution and Settlement; defendants will ensure that copies of the notice, Order and Resolution and Settlement are available for inspection at offices of the Department during regular business hours by class members and their parents, relatives and legal guardians, and all other interested members of the public. Defendants will make a reasonable number of copies of the above available to concerned individuals, local agencies, and consumer organizations.

(b) Current residents of Austin, Denton and Fort Worth State Schools, and their parents or guardians, shall receive copies of the attached notice by personal service or regular first class mail.

(c) The attached notice shall be published by defendants in at least one newspaper of general circulation in each of the following communities: Austin, Denton and Fort Worth. Such publication shall occur once in a Wednesday and once in a Sunday edition in the news sections of the newspapers.

Defendants will immediately begin to provide the notice required by this paragraph and will complete it not later than 45 days before the Resolution and


Settlement approval hearing. Defendants will file an affidavit that the class notice has been accomplished, such affidavit to be filed upon completion of the notice.

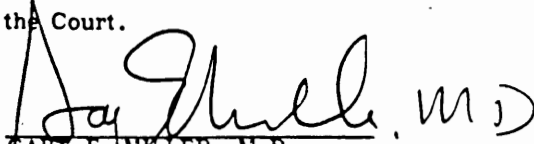
VII. Costs and Fees


45. Plaintiffs are entitled to an award of costs, including attorneys' fees, from defendants (pursuant to, e.g., 42 U.S.C. 1988).

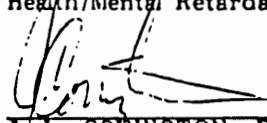
VIII. Parties Approval


45. Plaintiffs, by their counsel, and defendants by their Commissioner and counsel, stipulate and agree to the above terms. The defendants' agreement is subject to approval by the Texas Board of Mental Health and Mental Retardation, certification of which will be filed with the Court.


DAVID FERLEGER, ESQUIRE
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Phila., Pa. 19103
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GARY E. MILLER, M.D.
Commissioner
Texas Department of Mental
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Attorney General of
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ATTORNEYS FOR PLAINTIFFS

ATTORNEYS FOR DEFENDANTS



Gary E. Miller, M.D.
Commissioner

Texas Department of Mental Health and Mental Retardation

Central Office

P.O. Box 12668 • Austin, TX 78711-2668 • (512) 454-3761

Person for identification + us to
Post FOREVER

January 3, 1985

TO: Management and Program Staff, Central Office
Superintendents, State Schools for the Mentally Retarded
Directors
Amarillo State Center
Beaumont State Center
Rio Grande State Center
Executive Directors, Community MHMR Centers

FROM: Gary E. Miller, M.D.
Commissioner

SUBJECT: Compliance with Resolution and Settlement in Lelsz v. Kavanagh
Board Policies

On December 7, 1984, the Texas Board of Mental Health and Mental Retardation adopted a set of policies and directives which will enable the Department to more effectively meet the requirements of the Lelsz Resolution and Settlement. A copy of these policies and directives is attached. The Board also directed that additional action be taken with respect to the following three points:

- 1) Strengthen parents and guardians involvement in placement decisions under the ME Person's Act and by internal administrative review for those parents not provided that involvement under the Act.
- 2) Clarify TDMHMR responsibility for state school residents provided educational services by local independent school districts.
- 3) Specify what the decision making process will be concerning readmissions to state schools of persons placed from schools incorporating appropriate involvement of parents and guardians.

Recommendations are now being prepared to resolve these three issues.

If you have any questions regarding these policies or directives, please contact the appropriate Assistant Deputy Commissioner with whom you work.



Gary L. Miller, M.D.
Commissioner

Texas Department of Mental Health and Mental Retardation
Central Office

P.O. Box 12668 • Austin, TX 78711-2668 • (512) 454-3761

RESOLUTION AND SETTLEMENT IN LELSZ V. KAVANAGH
POLICIES OF
THE TEXAS BOARD OF MENTAL HEALTH AND MENTAL RETARDATION

BOARD POLICY I

Individuals with mental retardation shall receive services in their own local communities whenever appropriate and feasible. Services provided on the campus of state schools and state centers, however, are appropriate and beneficial for some mentally retarded persons. Therefore, the Board, through its budget-approval and policy-making roles, shall endeavor to support with adequate resources the state schools and state centers as well as the development of an expanded range of alternative programs in the communities of Texas.

While such expansion of the range of community services is essential to provide a balanced and effective delivery system for mentally retarded persons, the Board does not view this necessary expansion as eliminating the need for state schools and state centers. Therefore, the Board reaffirms its policy of the permanency of the state schools and state centers as a vital part of our service network and the need to expand the range of community alternatives available to people with mental retardation.

BOARD POLICY II

The Board of TDMHMR reaffirms its commitment to direct available departmental resources to implement the Lelsz Resolution and Settlement and to extend the client services obligations of Lelsz to all clients served by state schools, state centers, and community MHMR centers. Therefore, the Commissioner, the Department and all grant-in-aid and contract recipients of funds appropriated to the Department, are to apply available resources on a priority basis to bring the Department into full compliance with all provisions of the Lelsz Resolution and Settlement.

In accordance with these policies and in furtherance of previously approved policies of this Board, the Commissioner is authorized and directed as follows:

A. To authorize and encourage state schools and state centers to use available resources, including on-campus residential funds, to provide or secure community services for state school and state center residents when such services are deemed appropriate by the interdisciplinary treatment team (IDT). This directive is to be carried out according to the following principles and limitations:

1. Active and appropriate involvement of clients, parents and guardians in the IDT process is essential. The Department shall establish procedures to encourage clients, parents and guardians to participate in placement decisions, subject to the relevant provisions of the Mentally Retarded Persons Act.

2. An individual placed from a state school or state center campus to an off-campus residential program pursuant to this directive shall be readmitted to an on-campus residential program should such an admission become necessary notwithstanding any other Department policy, rule or regulation.
3. The staff-to-client ratios in on-campus residential programs of state schools and state centers shall not be reduced below the average for the preceding 12 months as a result of community placements made pursuant to this directive.
4. The Department assumes responsibility for provision of residential services to all persons now served by state school and state center residential programs for as long as they require and desire services.
5. Community residential placements made pursuant to this directive shall be tailored to the needs of individual clients. Since needs vary significantly among clients, a range of residential alternatives will be necessary. Such residential alternatives include, but are not necessarily limited to, the client's natural home, foster homes, personal care homes, group homes and apartments, and community based ICF-MR facilities.
6. The Department shall seek to secure appropriate residential alternatives for persons proposed for state school admission. The

Deputy Commissioner for Mental Retardation shall review each proposed admission to a state school to determine whether all reasonable steps have been taken to secure an appropriate alternative, and shall approve all state school admissions on an individual basis. Such decision shall be made as expeditiously as possible.

7. The Department shall continue its efforts to improve and refine its standards for institutional and community residential facilities.
8. The quality of all MR residential placements made pursuant to this directive shall be ensured through the establishment of specific monitoring procedures, administered by the Department. In addition, the Board recognizes and encourages additional monitoring by agencies and organizations external to the Department. In assessing the quality of residential placements, monitors shall pay particular attention to habilitation services aimed at improving the quality of life and the personal and social growth of clients, and integrating clients into the mainstream of community life.
9. Department staff will make all reasonable efforts to more effectively utilize TDNHRM appropriated funds through the use of generic services and by encouraging other public and private agencies to share in the cost of providing community services.

10. An individual placed in a community residence pursuant to this directive shall receive appropriate habilitation and support services equal or superior to those provided to him or her in the on-campus residential program from which he or she was placed.
 11. Persons in on-campus and off-campus residential programs shall live in residences that meet applicable physical plant standards. This directive shall be implemented in a manner which leads as rapidly as possible to the exclusive use of facilities which meet such standards.
- B. To identify legal, programmatic, financial and attitudinal barriers to community residential services and to take all reasonable steps to eliminate such barriers.
- C. To revise and reconstitute the register for residential placement. The revised register will reflect individual needs--met and unmet--of all mentally retarded persons who have undergone a comprehensive diagnostic and evaluation procedure by a component of the TDMHMR service system and are deemed eligible for residential or non-residential services.
- D. To make every reasonable effort to secure the Home and Community Care Waiver as a mechanism for increasing federal funding for community-based services and to utilize funds made available through the Waiver to maximize the extent of the Department's compliance with the Lelsz Resolution and Settlement.

- E. To utilize all available and appropriate resources to develop and carry out a systemwide training program geared to improving the skills, performance and knowledge of all system personnel involved in meeting the requirements of the Lelsz and R.A.J. settlement agreements.
- F. To calculate the costs of services provided to mentally retarded persons. Such cost determinations shall be used to compare the costs and benefits of alternative residential programs and to compare programmatically similar or equivalent programs operated by different entities or in different regions of the state.
- G. To develop a strategic plan for implementing these policies for achieving compliance with all provisions of the Lelsz Resolution and Settlement. The strategic plan shall include the names of individuals responsible for accomplishing specific tasks and dates by which the tasks shall have been accomplished.

BOARD POLICY III

Recognizing that services to infants and young children should be provided in as home-like and nurturing an environment as possible, it is the policy of this Board that:

- a. Children ages 0 through 6 receive priority for placement in off-campus residences.

- b. Children ages 0 through 6 not be placed in on-campus state school or state center residential programs or in any other non-home residential program except with the express approval of the Deputy Commissioner for Mental Retardation. Such decision shall be based on an analysis of the child's needs, disabilities, and current conditions; and shall be made as expeditiously as possible.
- c. The Commissioner work with the commissioners of the Texas Department of Health, Texas Department of Human Resources, Texas Education Agency and with the Texas Health and Human Services Coordinating Council to identify appropriate agency responsibilities for services to children ages 0 through 6.

BOARD POLICY IV

To ensure that school-age clients of the Department receive the benefits and rights afforded them by The Education of All Handicapped Children's Act (Public Law 94-142), it is the policy of this Board that:

- a. The Department actively collaborate with Texas Education Agency toward meeting the TEA's responsibility as the single state agency responsible for ensuring the education of persons ages 3 through 21.
- b. Persons ages 6 through 21 (except in emergencies) shall not be admitted to residential services of state schools and state centers

unless prior arrangements for educational services have been made with the local independent school district. [With the exception of admissions under the provisions of 46.02, Code of Criminal Procedure, and 55.03, Texas Family Code, the Deputy Commissioner for Mental Retardation shall approve each admission of an individual age 6 through 21 to a state school or state center. Such decision shall be made as expeditiously as possible. The Deputy Commissioner's decision shall be based on a determination that (1) the person will receive appropriate educational services or (2) an emergency exists which creates a clear overriding necessity for admission. In cases where a person is admitted to a state school or state center pursuant to any emergency, the Department shall attempt to obtain appropriate educational services for the person as quickly as possible.]

- c. Persons under the age of 22 currently in state schools and state centers shall be given priority for community residential placements
- d. The Department shall work with the Texas Education Agency and local school officials to develop a plan by March 15, 1985 describing the process by which eligible clients residing in state facilities may be afforded the opportunity to receive educational services through local independent school districts. (The Board recommends that the implementation of this plan commence no later than September 1, 1985 and that the plan be fully implemented within six years of that date.)

APPENDIX I
Limited Guardianship

LIMITED GUARDIANSHIP

- I. Basic idea and purpose of guardianship
 - A. Guardianship is a protective device
 - B. Types of guardianship for mentally retarded person
 1. Plenary guardianship (also called "full" or "total" guardianship)
 2. Limited guardianship (also called "partial" guardianship)
- II. Powers a limited guardian might be granted
- III. Alternations to limited guardianship - trusts; cosigner, guarantors and insurors; temporary guardianship
- IV. How to obtain a limited guardianship for a mentally retarded person
 - A. The importance of having a lawyer
 - B. Who applies for the limited guardianship
 - C. Who may be selected limited guardian
 - D. Where the hearing is held
 - E. Costs
 - F. Who must be told in advance about the hearing
 - G. Examination of the person thought to be mentally retarded
 - H. The hearing
 - I. Limited guardian's oath and bond
 - J. Court's order gives authority to the limited guardian
 - K. Court appointment of a successor limited guardian
 - L. Duties of limited guardians

APPENDIX J

Definitions

DEFINITIONS

1. **Mental Retardation:** A condition characterized by significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period.
2. **Subaverage General Intellectual Functioning:** A person possesses a measured IQ of more than two standard deviations below the mean of an appropriate instrument.
3. **Adaptive Behavior:** The effectiveness or degree with which the individual meets the standards of personal independence and social responsibility expected of the person's age and cultural group. A table of descriptions and illustrations of expected behavior has been developed by the American Association on Mental Deficiency (AAMD) to guide in determining adaptive behavior level. (See Manual on Terminology and Classification in Mental Retardation, 1973, AAMD)
4. **Developmental Period:** The period of a person's life which begins at conception and extends to the age of eighteen years. The requirement that mental retardation manifest itself during the developmental period serves to distinguish the condition of mental retardation from other disorders of human behavior.
5. **Mentally Retarded Person:** A person determined by a comprehensive diagnostic and evaluation study to have the condition defined as mental retardation.
6. **Moderately Retarded:** A person possesses a measured IQ of more than three standard deviations below the mean of an appropriate instrument existing concurrently with Level II adaptive behavior as described in the Manual on Terminology and Classification in Mental Retardation, 1973, prepared by the American Association on Mental Deficiency (AAMD).
7. **Residential Facility for the Mentally Retarded:** A facility of the Texas Department of Mental Health and Mental Retardation that provides twenty-four hour services, including domiciliary services, for the mentally retarded.
8. **Community Mental Health and Mental Retardation Center:** An entity organized pursuant to Article 5547-203, Vernon's Texas Civil Statutes, which provides mental retardation services.

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9. **Mental Retardation Services:** Programs and assistance for mentally retarded persons and may include, but is not limited to, diagnosis and evaluation, education, recreation, special training, supervision, care, medical treatment, rehabilitation, room and board, and counseling, but does not include those programs or assistance which have been explicitly delegated by law to other State agencies.
10. **Client:** A person receiving mental retardation services from the Texas Department of Mental Health and Mental Retardation.
11. **Least Restrictive Alternative:** A program, treatment, or environment appropriate to the client's needs and which is the least confining or structured for the client's condition.
12. **Comprehensive Diagnosis and Evaluation:** A study including a sequence of observations and examinations of a person leading to conclusions and recommendations formulated jointly, with dissenting opinions, if any, by an interdisciplinary team. The study shall include but not be limited to the following procedures:
 - A. **Medical Evaluation**
 1. Visual Screening
 2. Hearing Screening
 3. Routine Laboratory Tests (urinalysis, Tuberculin Testing, hematologic or blood chemistry tests, and so forth.)
 4. Neurological Screening, if indicated
 5. Identification of other possible dysfunctions which would cause handicaps creating difficulty for a person in adapting to his or her environment.
 6. Referral to medical specialists such as, but not limited to, neurologist and audiologist, where the evaluation indicates the need.
 - B. **Psychological Evaluation**
 1. Intellectual Appraisal
 - a. Traditional instruments
 - b. Culture-free instruments, if available
 2. Achievement Tests as appropriate
 - a. Educational
 - b. Vocational
 3. Tests for Organicity

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4. Personality Tests and other measures as appropriate.
 5. Referral to specialists; such as, but not limited to, psychiatrists and neurologists, where the evaluation indicates the need.
- C. Adaptive Behavior Evaluation
1. AAMD Adaptive Behavior Scale and other measures of adaptive behavior, as appropriate.
 2. Observation
 3. Clinical Conclusions
- D. Social History/Evaluation
1. Inquiry into the person's immediate and historical environment.
 2. Inquiry into the person's present cultural and social situation.
 3. Descriptions of the person's behavior (positive and negative) in the community environment.

Following the gathering of data by means of observations and examinations, a team of professionals representing at least the areas of medicine, psychology, social services, and any other relevant area, as well as, if appropriate, the client, his parent, guardian or advocate, will meet as an interdisciplinary team to consider the applicant and reach a consensus as to the existence of mental retardation, specific needs of the person, and recommended program placement.

13. Interdisciplinary Team: A group of persons professionally qualified, certified, or both, in various professions with special training and experience in the diagnosis, management, needs and treatment of mentally retarded persons and in the delivery of mental retardation services that functions as a team. Each team member shall consider all information and recommendations so that a set of unified and integrated team conclusions and recommendations is devised.
14. Individual Program Plan (IPP): A written plan of intervention and action that is developed, and modified as appropriate, by the interdisciplinary team. Goals and objectives are specified separately and within a time frame and in behavioral terms that provide measurable indices of progress and enable the effectiveness of intervention to be evaluated. Modes of intervention for stated

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objectives are specified, and responsibility for service delivery is identified. The Individual Program Plan (IPP) is sometimes referred to as a "Habilitation Plan."

15. Resident of the State:
 - A. A person who
 1. physically resides in Texas, and
 2. intends to remain in Texas indefinitely or who has no present intention to leave, and
 3. is able to show that residence in any State other than Texas has been abandoned.
 - B. A person who has established his residency in Texas but is temporarily absent from the State.
 - C. A military dependent who is a minor and whose parents' residence of record is Texas.
16. Placement: The assignment of a client to a program or to a residential facility for the mentally retarded for the purpose of receiving appropriate care, treatment and training.
17. Regular Placement: A placement which is made only after a temporary placement. The regular placement is time specific, and it will be reviewed and updated at least annually. Renewal of regular placement is allowed as the needs of the client indicate. Renewal of regular placement requires that the habilitation plan be updated and that a new agreement between client, parent or guardian and facility be executed.
18. Temporary Placement: A placement made for a maximum period of six (6) months and is renewable in succession only once. Renewal of temporary placement requires meeting the criteria and procedures for an initial temporary placement.
19. Emergency Placement: A placement made for a maximum period of thirty (30) days. An emergency placement is not renewable in succession. If care is needed beyond the initial period, the client, parent, or guardian may make application for a temporary placement.
20. Client transfer: The transfer of a client to another residential facility for the mentally retarded or to a residential mental health facility. The facility to which the client is transferred assumes total responsibility for the care, treatment and programming of the client.

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21. **Client Furlough:** The client is physically absent from the facility longer than 72 hours for program purposes. Final responsibility for the care, treatment and programming of the client remains with the residential facility for the mentally retarded; however, the facility is relieved of all legal responsibility while the client is physically absent from the facility. There are three basic types of furlough:
 - A. **Short-term Furlough:** Includes furloughs for such purposes as a visit home; and
 - B. **Long-term Furlough:** Furloughs for such purposes as a trial placement for alternate care; that is, a "trial alternate placement."
 - C. **Temporary Furlough:** A placement of a client in a residential facility for the mentally ill under Section 16 of the Mentally Retarded Persons Act, Article 3871b, V.A.C.S.
22. **Client Discharge:** The client physically leaves the residential facility for the mentally retarded and is no longer considered a client of the school for program purposes. Upon the discharge of a client, all responsibility for the care, treatment and training of the client by the residential facility is dissolved.
23. **Department:** The Texas Department of Mental Health and Mental Retardation.
24. **Commissioner:** The Commissioner of the Texas Department of Mental Health and Mental Retardation.
25. **Superintendent:** The superintendent or director who is the administrative head of a Department facility.
26. **Deputy Commissioner:** The Deputy Commissioner of Mental Retardation Services of the Texas Department of Mental Health and Mental Retardation.
27. **Coordinator of State School Admissions:** The person on the staff of Mental Retardation Services in the Central Office of the Department who is responsible for monitoring and maintaining the Central Waiting List.
28. **Central Waiting List:** The statewide registry of persons seeking admission to a residential facility for the mentally retarded.

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29. Client's Residential Facility or Current Placement Facility: The Department or other facility in which the client currently resides and from which transfer or furlough to another facility is contemplated or proposed.
30. Destination Facility: The Department or other facility to which transfer, furlough or discharge of a client is contemplated or proposed.

Community Services Division
Denton State School
May 2, 1977

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