VARIABLES INFLUENCING FAMILY MEMBERS' DECISIONS REGARDING CONTINUED PLACEMENT OF FAMILY MEMBERS WITH MENTAL DISABILITIES IN ONE STATE-OPERATED INSTITUTION

A Dissertation

by

ALEX DON COLVIN

Submitted to the Office of Graduate Studies of
Texas A&M University
in partial fulfillment of the requirements for the degree of

DOCTOR OF PHILOSOPHY

December 2006

Major Subject: Curriculum and Instruction

VARIABLES INFLUENCING FAMILY MEMBERS' DECISIONS REGARDING CONTINUED PLACEMENT OF FAMILY MEMBERS WITH MENTAL DISABILITIES IN ONE STATE-OPERATED INSTITUTION

A Dissertation

by

ALEX DON COLVIN

Submitted to the Office of Graduate Studies of
Texas A&M University
in partial fulfillment of the requirements for the degree of

DOCTOR OF PHILOSOPHY

Approved by:

Chair of Committee,	Patricia J. Larke
Committee Members,	Gary E. Briers
	LaVerneYoung-Hawkins
	Alvin Larke Jr.
	Linda Parrish
Head of Department,	Dennie Smith

December 2006

Major Subject: Curriculum and Instruction

ABSTRACT

Variables Influencing Family Members' Decisions Regarding Continued Placement of Family Members with Mental Disabilities in One State-Operated Institution.

(December 2006)

Alex Don Colvin, B.S.W., Prairie View A&M University;
M.S.W., University of Houston
Chair of Advisory Committee: Dr. Patricia J. Larke

The purpose of the study is to identify variables influencing family members' decisions regarding continued placement of family members with mental disabilities in state-operated mental retardation institutions.

This study was conducted during the spring and summer of 2006 (March through July). The participants were 51 family members of residents residing in one state-operated institution. The survey questionnaire used in this study was developed using several similar questionnaires found in the literature as a guide. Of the 17 questions, two were taken from the Survey of Families with a Developmentally Disabled Family Member by Tausig (1985); and two were taken from the Survey of Parents of Children with Developmental Disabilities by Sherman (1988). The remaining questions were generated and modified from the National Survey of the Families of Institutionalized Mentally Retarded Persons by Spreat, Telles, Conroy, Feinstein, and Colombatto (1987). All three questionnaires used were designed to assess families' perceptions of residential services.

Descriptive statistics were used to report personal characteristics of family members, and correlation techniques were used to measure relationships between and among characteristics of family members and their decisions to both seek and maintain placement of their family member with mental disabilities in a state-operated institution.

Major findings are:

1. Respondents were more likely to seek initial placement in a state mental retardation institution, a) because their family member with the mental disability could receive more intensive care and/or specialized programs in the institution, and b) because they were advised by physicians and/or other medical and professional specialists.

2. The need for a more protected place/secure environment was very important to family members when deciding to seek initial placement.

3. Current placement was maintained because their family member with the mental disability could receive more intensive care or specialized programs in the institution.

4. The need for 24-hour supervision that could provide for a more protected environment was reported as a reason for the decision to maintain their current placements.

5. Respondents indicated they were satisfied with services provided at the residential facility; and the need for facility, social and physical/health supports were important factors that determined family members’ choices to maintain placement.

DEDICATION

To Mama –

Words cannot express how much you have been an inspiration to me. God has truly blessed me with a beautiful and wonderful mother. You have been a great role model and a support for me throughout my life. Always encouraging me to be confident in who I am and to reach for the stars. When times became tough in my life, you had the right words to make everything better. I can always count on my Mama. You lead the family with class, grace, and integrity, never unwilling to give of yourself to help me in anyway. Thanks for always being my greatest cheerleader. I love you.

Alex Don

To My Family-

You all have been great gifts to me from Heaven above. God has been so good to me to provide me with two blessings in Allyson and Alex. Seeing the two of you struggle for life as babies has been my inspiration. You two have helped me understand that God is in control and to lean on him. Your fighting spirits helped me to understand that all is possible when we place our hands in the Master's hands. I pray that I can be an inspiration to you as you mature throughout life. To my wife Amy, I dedicate to you this dissertation. God has been so gracious to provide me with you. You are a wonderful person, a beautiful wife, and my closest friend. You have been an amazing support to me. I love you all.

ACKNOWLEDGEMENTS

It has been an extreme blessing to have so many positive people in my life. Therefore, I wish to thank several special people for their assistance in helping me reach this milestone. But first, I would like to thank God for walking with me and carrying me. He has brought me through this and that and I am very grateful to him who reigns from above. If it had not been for God on my side, especially throughout this process, my accomplishments would not have been possible.

God has truly smiled on me by providing me with the best supports possible. I am grateful to my parents and family for their continued encouragement and support. To my mother and father Alton and Alguree Colvin for encouraging me to be the best I can be. Thanks for instilling Christian values in me and to seek God for all my help. To my father, I wish to thank you for teaching me good work ethics and how to be a strong man. To my mother, I thank you for continually reinforcing that there were no boundaries to what I could accomplish. Thanks for pushing me and always being supportive of my endeavors to go further as I pursued my education. You have always encouraged me to reach for the skies. Thank you mama and daddy, I love you. I am thankful to my brothers and sister for your support and for believing in me and encouraging me.

I would like to also acknowledge my longtime teacher, mentor, and friend, Mrs. Elizabeth Martin, whom I credit for instilling in me the confidence to be the best I can be. You deserve special recognition for teaching me to excel. Thanks to you for seeing something in me that I did not see in myself. You deserve my gratitude and thanks.

I wish to thank my committee chair Dr. Patricia J. Larke, for all your assistance through this process. Your continued help, generosity with your time, and encouragement has been invaluable for me through this process of producing this dissertation. Thanks and gratitude are also due to each of my committee members, Dr. Alvin Larke Jr., Dr. Linda Parrish and Dr. LaVerne Young-Hawkins for giving unselfishly in providing me with guidance and feedback. Also for your patience and support throughout this process. I extend a special thank you to Dr. Gary Briers for his time in helping me analyze the enormous amount of data collected. I appreciate your friendly demeanor, expertise, and patience with me. I would like to also offer my sincere gratitude to Dr. Wash Jones for assisting me with editing my dissertation. Your attention to detail and suggestions helped to make my work the best it could be. Thanks for being a great resource for me. A special thanks goes to Dr. Alvin Larke Jr., for being an inspiration to me. Thanks for being my teacher, my brother in Christ and my friend. I sincerely appreciate your encouragement and support. Thanks for your listening ear and praying with me, especially when I became discouraged and had doubts about this doctoral work, you helped me know that I could accomplish this goal.

I would like to acknowledge the Superintendent and staff at Southwood State School for all your assistance in this study. I appreciate the generous help and assistance provided to me through the use of your facility to conduct my study. I would like to extend a special thank you to Gloria Hendrickson for unselfishly sharing your valuable time and energy with assisting me to get surveys mailed and re-mailed to the family

members. I would also like to thank the family members' who agreed to participate in the study. Without your help this research would not have been possible.

Additionally, I would like to acknowledge the assistance of two very special people who have been invaluable to me throughout this process. Vicki and Olivia, thanks for your help with reading, proofing, and typing for me and listening and supporting me through my periods of frustration and joy. You really have no idea how special you two were to me. God has blessed me to have the best support staff in the world. Thank you.

Acknowledgements are also due to my colleagues and friends at Brenham State School. Special thanks go to you Debra for the support, suggestions, and encouragement you provided me while I labored through my studies. You know that you have been a great friend to me through the years.

A special acknowledgement goes to my church family New Life Church of God. Thanks for all your prayers and support in this endeavor.

Finally, I would like to acknowledge my wife, Amy, for your encouragement and support during this entire process. Thanks for supporting me when I chose to begin this journey and listening, encouraging, and praying with me as I progressed through my studies and dissertation. Thanks for sacrificing your time and providing your assistance where you could. I would also like to thank my children, Allyson and Alex for being patient and allowing daddy time to get his work done. Thanks for putting up with me when I seemed irritated. Daddy loves you.

TABLE OF CONTENTS

Page

ABSTRACT ……………………………………………………….........................iii

DEDICATION …………………………………………………….............................v

ACKNOWLEDGEMENTS …………………………………….........................vi

TABLE OF CONTENTS ……………………………………….........................ix

LIST OF TABLES ………………………………………….............................xi

CHAPTER

I INTRODUCTION …………………………….…………….......................1

- Background of the Study ……………………………..........................1
- Statement of the Problem ………...………………..…..........................5
- Purpose and Objectives of the Study ……………….............................6
- Research Questions …………………………………..........................7
- Significance of the Study ………...………………….........................7
- Definition of Terms ……………………………………..........................8
- Assumptions ……………………………………….........................10
- Limitations ……………………………………….............................10
- Organization of the Study ……………………….............................11

II REVIEW OF LITERATURE ………………………….........................12

- Historical Overview of Institutions and Care and Treatment of Those With Mental Retardation ….………………………………………….....13
- Treatment in Facilities……..........…......……………………………........25
- Call for Institutional Reform………...................................………….......32
- Legislation and Court Decisions Impacting Institutional Services for Individuals with Mental Retardation …..35
- Historical Overview of the Origin of Institutions in Texas ……….......45
- Legislation and Court Decisions Impacting Institutional Services for Individuals with Mental Retardation in Texas…………………………......49
- Normalization, Family Member Perceptions, and Factors for Placement. 53

TABLE OF CONTENTS (Continued)

CHAPTER Page

III METHODOLOGY ……………………………………………………........61

Research Design ……………………………………………...........61
Population …………………………………………………….........62
Participants…………......…………...............................……….........64
Instrumentation ……………………………..64
Pilot Test of the Instrument…..…………...66
Collection of Data ………………………………………….............67
Analysis of Data ………………………………….........................70

IV FINDINGS AND DISCUSSION ………………………………...........72

Demographic Information ………………….……..........................73
Findings Related to Question 1 ……………………..........................83
Findings Related to Question 2 ……………………..........................86
Findings Related to Question 3 ……………………………….............90
Findings Related to Question 4 ………..………………….……….............93

V SUMMARY, CONCLUSIONS, AND
RECOMMENDATIONS ………………………………………...........97

Summary ………………………………………………….............97
Conclusions …………………………………………………............100
Recommendations for Future Research …………....................................106

REFERENCES ……………………………………………………...........109

APPENDIXES ……………………………………………………...........122

APPENDIX A …………………………………………………….............123

APPENDIX B …………………………………………................................125

APPENDIX C ……………………………………….................................127

APPENDIX D ………………………………………..............................129

APPENDIX E ………………………………………..................................133

VITA ………………………………………………………………..........140

LIST OF TABLES

TABLE Page

4.1 Age of Respondents ……………………………………………......................75

4.2 Gender of Respondents …………………………………….….……............76

4.3 Relationship to the Person with the Disability…………………….............76

4.4 Marital Status at Time of Initial Placement……………………….............77

4.5 Current Marital Status of Respondents ……………….………….........77

4.6 Ethnicity of Respondents ……………………………….......................77

4.7 Education of Respondents ……………………………………………............78

4.8 Education of Respondents’ Spouses ………………………………...........78

4.9 Income of Respondents ………………………………………………...........80

4.10 Forms of Financial Assistance………………………….........................80

4.11 Identified Developmental Disabilities……………….……….............82

4.12 Levels of Mental Retardation ………………………………………..........82

4.13 Circumstances Influencing Respondents’ Decisions to Seek Initial Placement ………………………………………………………..........85

4.14 Variables Influencing Respondents’ Decisions to Seek Placement ……………………………………………………………........85

4.15 Circumstances Influencing Respondents’ Decisions to Maintain Placement …….…………………………………………………...........89

LIST OF TABLES (Continued)

TABLE Page

4.16 Variables Influencing Respondents' Decisions to Maintain Placement..89

4.17 Variables on Services Provided by the Facility...92

4.18 Personal Support Variables..96

CHAPTER I

INTRODUCTION

Background of the Study

Within the past twenty years, several challenges have confronted the field of mental retardation within the United States. The issue of care and treatment provided in institutions has been at the forefront. Continued service provision within institutions and the need for the expansion of residential services to people with mental retardation from large public settings to smaller settings in the community also have created challenges (Felce, Thomas, DeKock, Saxby, & Repp, 1985; Rotholz & Massey, 1996). The changing philosophies of professionals and state agencies over the years have influenced many of the challenges on how best to serve individuals with disabilities (Bogdan, Biklen, Blatt, & Taylor, 1981; Rosen, 1994; Schalock, 1990; Wolfensberger, 1972).

From the beginning of institutionalization in the United States in 1848, until about three decades ago, individuals committed to institutions had increased steadily. In 1904, 14,000 residents were being served in state-operated institutions in the U.S., and, by 1970, the total number of residents served in institutions for the mentally retarded topped 200,000 (Scheerenberger, 1976). However, for the past several decades, the national trend has shown that states steadily have decreased the number of individuals served in state – operated institutions (Anderson, Lakin, Mangan, & Prouty, 1998).

Between 1968 and 1991, the number of individuals with mental retardation served in state facilities declined between three and four percent annually (Braddock,

---

This dissertation follows the style of the *American Journal on Mental Retardation.*

1991). Additionally, between 1988 and 1997, the number of individuals served in large, state residential facilities declined by nearly 70 percent nationwide (Prouty & Lakin, 1997). Moreover, Braddock reported that, in 1990, the residential census of the nation's state schools fell below 90,000 persons. In terms of actual populations, between 1985 and 1995, resident populations in residential facilities decreased by 45,852 and between 1995 and 2005 resident populations decreased by 23,328. Between 1980 and 2005, the average daily population of large state facilities for persons with developmental disabilities decreased by 69.2% (Coucouvanis, Lakin, Prouty, & Webster, 2006).

This drop in the number of residents served in state-operated institutions was not just the result of happenstance, but the result of two factors: (1) the concerted effort by many parents and professional groups such as the Association for Retarded Citizens (the ARC) (Larson & Lakin, 1989) who had advocated for change in the lives of individuals with mental retardation and came out in support for deinstitutionalization of institutions; and (2) legislation and class action suits such as *Pennhurst v. Hardermann* (1977), which ruled that rights for people with mental disabilities residing in institutions were being violated because isolation and confinement were counterproductive to habilitation (Scheerenberger, 1983). According to Scheerenberger (1976) and Hayden (1998), allegations of subhuman conditions and treatment in many institutions were voiced, along with violations of rights to due process, education, and equal protection for persons served. These concerns were exacerbated further by media exposes in the early 1970s that revealed to the public the deplorable conditions and treatment to which residents with mental disabilities were subjected (Braddock, 1990; Anderson, Lakin, Mangan, & Prouty, 1998). Researchers Kleinberg and Galligan (1983) made two salient assumptions: (1) institutions do not appear to engender client growth, and (2) community homes are more “normalizing” environments than institutions.

However, despite reports by professionals, program planners, and advocate groups of the increasingly accepted goal of deinstitutionalization, closure of institutions, and the commitment to community-based alternatives, not everyone is enamored equally with this movement (Spreat, Telles, Conroy, Feinstein, & Colombatto, 1987). Ferguson (1978) suggested that sufficient attention has not been paid to the desires and concerns of all families of persons with mental disabilities. Ferguson asked:

> What about the position and feelings of the parents? Have we solicited their responses and feelings? Some of the strongest objections and legitimate concerns have been expressed by parents. Shouldn’t we also consider their needs? (p.6)

Similarly, Colombatto, Isett, Roszkowski, Spreat, D’Onofrio, and Alderfer (1982) reported that superintendents of public residential facilities believed that such families had not been polled adequately for their views on deinstitutionalization. Many parents publicly and privately have resisted deinstitutionalization on the basis of negative perceptions (Larson & Lakin, 1991). Likewise, many families and parent organizations have voiced their opposition to deinstitutionalization efforts and support keeping institutions open (Hayden, 1998). For instance, past research established the fact that families of residents in public institutions were highly satisfied with these facilities (Spreat, Telles, Conroy, Feinstein, & Colombatto, 1987). In their review, Keating, Conroy, and Walker (1980) found as part of the Pennhurst Longitudinal Study that 83 percent of families were “satisfied” or “very satisfied” with Pennhurst, even at the height of court and media criticism of Pennhurst. Moreover, 72 percent strongly opposed the idea of community placement. Also, Atthowe and Vitello (1982) detected similar feelings among families in New Jersey. In their survey, 54 percent of families surveyed expected no more than custodial care, and 91percent said the institutional care was adequate or better. Subsequently, more than 80 percent wanted their relatives to remain in New Jersey's institutions.

Larson and Lakin (1991) identified several concerns voiced by parents about deinstitutionalization. Generally, they found parental concerns included a perception of the superiority of an institutional environment and fear of potential problems in community settings. Other major concerns addressed by family members of persons with mental disabilities included finding and maintaining a safe, caring, respectful, and permanent place to live. Many families experience strong feelings of uncertainty, fear, betrayal and guilt with movement (Conroy, 1985; Mitchell, 1988). While many of these parents have expressed a willingness to accept group homes, as a means of meeting the residential care needs for some people, they appear to have a distinct preference for the institution for their family members instead of a group home. Therefore, attention to parental attitudes and perspectives should be an important feature in planning and providing services (Larson & Lakin, 1991).

Though research findings of residential settings have not been definitive, what findings do suggest is that strong views regarding whether to institutionalize, continue institutionalization, or to deinstitutionalize often have been contradictory. Consequently, more research is necessary to examine the position of parents affected by this choice.

Statement of the Problem

Residential settings for people with mental disabilities are areas where little choice has been available. Three primary residential options exist for most people with mental retardation: public institutions, private institutions, and group homes (Blatt & Kaplan, 1967). As for large institutional facilities, shared views in the field have depicted these settings as dehumanizing and lacking in the basic and necessary opportunities for personal growth and development (Wolfensberger, 1991). According to Skeels (1966), institutional care retards personal care and development. Additionally, other early investigators consistently have documented declines in residents' IQ after institutionalization. Experimental studies have indicated that due to institutionalization, children with mental retardation are disadvantaged by decrements in performance on a number of tasks thought to reflect important cognitive processes, including the quality of language behavior, the level of abstraction on vocabulary tests, and the ability to form a learning set (Balla, Butterfield, & Zigler, 1974).

Despite these reports, family members have continued to request and/or seek placement for their family members with mental disabilities into state-operated mental retardation institutions. Researchers have identified variables that contribute to parents' decisions to seek these placements. Particularly, the degree of disability and level of functioning of the family member with the disability have been found to be highly related to the decision to place (Allen, 1972; Downey, 1965; Saenger, 1960). In several studies, factors such as family size, socioeconomic level, marital and family relations, parents' age and health status, and the presence of other family problems were identified as playing a role in the decision to seek residential care (Fotheringham, Skelton, & Hoddinott, 1972; Graliker & Koch, 1965; Wolf & Whitehead, 1975). Additionally, problems of families caring for a developmentally disabled person included interference with family life, difficulty in managing the individual's behavior, community rejection, and physical and time demands. Also, the availability of social supports and community service systems has exerted an important influence on a family's decision to seek out of home placement (Hill, 1958; McCubbin, 1979).

Lazarus (1966) noted however, that family caregiver reactions depend heavily on their subjective evaluation of the situation. Therefore, before a caregiver considers the institutional environment as their only viable choice, more reliable knowledge would be helpful to clinicians and parents faced with the difficult decision of whether or not to institutionalize or continue institutionalization of a child with mental retardation (Balla, Butterfield, & Zigler, 1974).

Purpose and Objectives of the Study

The general purpose of the study is to identify variables influencing family members' decisions regarding continued placement of family members with mental disabilities in state-operated mental retardation institutions. Additionally, this study will examine the impact of personal support variables such as physical/health, emotional, financial, facility and social supports on family members' decisions regarding continued placement of family members with mental disabilities in an institution. The study will be conducted using the family member/caregiver who knows the individual best as determined by a record of visits documented by the facility using visitor passes.

Research Questions

The following questions are examined in this study:

1. What variables do family members use to seek initial placement of family members with mental disabilities in state-operated mental retardation institutions?
2. What variables do family members use to maintain placement of family members with mental disabilities in state-operated mental retardation institutions?
3. How do family members assess the quality of services provided in a state-operated institution?
4. To what extent do personal support variables (emotional, financial, social, physical/health and facility) impact family members' decision to maintain institutional placement?

Significance of the Study

This study underscores the need for a more comprehensive examination of family members' views of institutionalization. Currently, a lack of research exists which assesses variables family members choose as important regarding continued placement of their family members with mental disabilities in state-operated mental retardation facilities (Balla, Butterfield & Zigler, 1974).

Definition of Terms

For the purpose of clarifying the problem statement in this study, the following terms of the study were defined:

Deinstitutionalization - the process of releasing as many children and adults as possible from the confinement of residential institutions into their local communities (Kirk & Gallagher, 1986).

Emotional – psychological stressors or changes that accompany the challenges of caring for a family member with a mental disability.

Family Members – can also be defined as caregivers who include the mother, father, mother and father responding together, sister or brother, aunt, uncle, or cousin who advocates for the individual.

Financial – income, cost, expenditures, or expenses associated with the support, care and treatment of a family member with mental retardation. This can include added expenses often tied to unemployment, lost chances for a job or advancement, which translates to reduced family income.

Intermediate Care Facilities with Mental Retardation (ICF-MR) – an institutional model of service that provides 24-hour, supervised care for individuals with a primary diagnosis of mental retardation or related conditions. These facilities provide medical care and supervision, nursing services, occupational and physical therapies, activity programs, educational and recreational services and psychological services. They also provide assistance with activities of daily living, including meals, housekeeping, and assistance with personal care and taking medications.

Institution/Facility – residential environments ranging from six beds to several hundred beds for persons who have mental retardation or a condition related to mental retardation. They provide residential and habilitative services, skills training and adjunctive therapies with 24-hour supervision and coordination of the individual program.

Living Environment - the places where an individual with mental retardation lives. For the purpose of this study, living environment either will be an institutional environment or a community environment when referring to a home in a community.

Mental Retardation -a significantly sub average general intellectual functioning that is accompanied by significant limitations in adaptive functions in at least two of the following skill areas: communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health and safety. The onset must occur before age 18 years. (DSM-IV; American Association on Mental Retardation, 2002).

Physical/Health – a personal change that makes it difficult to provide needed daily care. This can include (age of the family member or child, challenging behaviors, medical status of family member or child, size of child, etc.).

Personal Support Variables- include physical/health, facility, social, emotional, and financial supports.

Residential Services - services or supports received either in a state-funded intermediate care facility such as a state school or state-funded community-based group home.

Social Supports – an “exchange of resources between at least two individuals perceived by the provider or the recipient to be intended to enhance the well-being of the recipient” (Shumaker & Brownell, 1984). These include resources or networks available or accessible to family members to assist with the burden of care of family members with mental retardation such as respite services, community mental retardation authorities (MRA), social networks, relatives, neighbors, and friends. Additionally, this can include finding needed specialized professionals or systems.

Assumptions

1. Family members used will give an honest answer to the questions asked on the survey questionnaire.
2. The instrumentation used in this study to measure variables influencing family members’ decisions to maintain state institution placement measured the variables accurately.
3. Scores provided by the questionnaire instrument used for measurement in the study will be considered valid and reliable.
4. The data collected will reflect accurately the participants surveyed.
5. Family members may feel inclined to bias answers.

Limitations

1. The subjects for the study are limited to the family members of individuals residing in one state school in Texas.

2. Findings from this study may not be generalized to any group other than family members of individuals receiving services from Southwood State School. For the purpose of this study, Southwood State School is the proxy name used for the actual institution.
3. Family members that participate may give socially acceptable responses to questions on the questionnaire instrument.

Organization of the Study

Chapter I consists of an introduction of the study including the statement of the problem, research questions, purpose of the study, significance of the study, definitions, assumptions and limitations. Chapter II contains a review of literature pertaining to (1) historical overview of the origin of institutions (2) treatment in facilities, (3) call for institutional reform, (4) legislation and court decisions impacting institutional services for individuals with mental retardation, (5) historical overview of the origin of institutions in Texas (6) legislation and court decisions impacting institutional services for individuals with mental retardation in Texas and (7) normalization, family member perspectives and factors for placement. Chapter III outlines methods and procedures used to conduct the study. Chapter IV contains the analysis of data and discusses the findings of the study. Chapter V provides a summary, conclusion of the study and recommendations.

CHAPTER II

REVIEW OF LITERATURE

Historically, family members' of people with mental disabilities have faced many challenges over the centuries in an attempt to obtain appropriate services for their family members with mental disabilities. In an effort to understand better the issues facing family members in selecting a living environment for family members with mental disabilities, the review of literature will address the following topics: (1) historical overview of the origin of institutions (2) treatment in facilities, (3) call for institutional reform, (4) legislation and court decisions impacting institutional services for individuals with mental retardation, (5) historical overview of the origin of institutions in Texas (6) legislation and court decisions impacting institutional services for individuals with mental retardation in Texas and (7) normalization, family member perspectives and factors for placement.

The historical views on the origin of mental retardation will follow a chronological order to include: the international evolution of institutions, evolution of institutions in America, early 19th century philosophical stance on rehabilitation, shift in philosophical stance, beginning of parents movement, beginning of advocacy movement, expansion continues in 1950s and 1960s, Kennedy's impact, decade of legal issues, deinstitutionalization and normalization introduced, and depopulation of institutions.

Historical Overview of the Origin of Institutions and Care and Treatment of Those with Mental Retardation

Historically, service provision to those with mental disabilities has encountered numerous transitions with regard to care and treatment. This section provides an overview of historical events that have impacted services for people with mental disabilities.

International Evolution of Institutions

Biblical Beginning

From the beginning, mental retardation has been acknowledged and can be traced as far back in history as Luxor, Egypt, around 1500 B.C. Although somewhat vague due to difficulties in translation, early documents refer to disabilities of the mind and body due to brain damage (Sheerenberger, 1983). In fact, early references to defective individuals are mentioned in the Bible as well as in the Koran. Early religious leaders such as Jesus and Mohammed advocated for more humane treatment of individuals who were developmentally disabled. Jesus' mission frequently involved healing the blind, deaf, crippled, demonic, epileptic, dumb, and paralytic (Scheerenberger, 1983). His teachings and healings would have a tremendous influence on the future course of many attitudes and social development (Scheerenberger, 1983). Following his example, the Apostle Paul wrote, "Now we exhort you brethren, warn them that are unruly, comfort the feebleminded, be patient toward all men (1 Thessalonians 5:14). The Bible also links certain afflictions to sinfulness: "The Lord shall smite thee with madness and blindness and astonishment of heart" (Deuteronomy 28:28).

Additionally, the Koran, which was revealed to Mohammed by Gabriel, contained 114 chapters proclaiming tolerant treatment of those who were different: “Give not unto those who are weak of understanding the substance which God hath appointed you to preserve for them; but maintain them there out, and clothe them, and speak kindly unto them” (The Women 4.5). Though it may be easy to discern that individuals with mental retardation and other persons of disadvantage were readily caught up in the variables of thought, we will see the highly variable treatment of persons with mental retardation persist for centuries (Scheerenberger, 1983).

Middle Ages

At various periods of the Middle Ages and Renaissance, individuals with developmental disabilities were procured for amusement or other purposes (Scheerenberger, 1983). They were regarded as “fools and jesters,” and no steps were taken to enlighten them; some even proclaimed that this group was “filled with Satan” (Rosen, Clark, & Kivitz, 1976). During this era, people with mental disabilities in need of residential protection many times were cared for in one of a wide variety of institutions including monasteries, hospitals, charitable facilities, prisons, almshouses, pest houses, workhouses, warehouses, and other buildings most of which had lost their original usefulness (Scheerenberger, 1983).

17th and 18th Century

During the 17th and 18th centuries, as medicine made several significant strides forward, it began to play a role in mental retardation. One of the earliest acknowledgements occurred in 1690 when John Locke published his famous work entitled, “An Essay Concerning Human Understanding.” Locke believed that an individual was born without innate ideas and that the mind was a tabula rasa, or a blank slate. This profoundly influenced the care and training provided to individuals with mental retardation. He was also the first to make a distinction between mental retardation and mental illness; “Herein seems to lie the difference between idiots and madmen, that madmen put wrong ideas together and reason from them, but idiots make very few or no propositions and reason scarce at all” (Doll, 1962).

Victor’s Story. The first recorded actual attempt to teach a child with mental retardation occurred between 1794 and 1798 (Krishef, 1983). This cornerstone event in the evolution of the care and treatment of individuals with mental disabilities was the work of physician Jean-Marc-Gaspard Itard (Scheerenberger, 1983) who was hired in 1800 by the Director of the National Institute for Deaf-Mutes in Paris, France. Itard worked with a young boy named Victor, who had apparently lived his whole life in the woods of south central France and, after being captured and escaping several times, fled to the mountains of Aveyron. Around the age of 12, he was captured once again and sent to an orphanage. Found to be deaf and mute, Victor was moved to the Institute for Deaf-Mutes (Landesman & Vietze, 1987).

Upon Itard’s initial training with Victor, he soon discovered that Victor lacked the intelligence to do such basic tasks as climbing a chair to obtain food placed out of his reach (Krishef, 1983). It was Itard’s goal to try to make Victor, the “Wild Boy of Aveyron” as he came to be known, into a “normal” person (Landesman & Vietze, 1987). Itard developed a broad educational program for Victor to develop his senses, intellect, and emotions and, after two years of instruction, Victor appeared relatively normal in limited areas. He showed affection, was clean, and was able to read and understand several words (Krishef, 1983). However, after five years of training, Victor continued to have significant difficulties in language and social interaction though he acquired more skills and knowledge than many of Itard's contemporaries believed possible. Although receiving additional training, Victor made only slight progress in the use of sensory skills and no reliable skills in handling his emotions. Subsequently, Itard reluctantly ceased work with Victor (Krishef, 1983). Despite his limited success with Victor, Itard's educational approach became widely accepted and used in the education of the deaf. Almost suddenly, interest in educating individuals with developmental disabilities began to flare up in the first half of the 19th Century, spreading from France and Switzerland through the rest of the civilized portion of Europe and into the United States of America (Kanner, 1964).

An air of optimism developed among the physicians of this century, particularly among medical teachers of “deaf and dumb” individuals as they entertained hopes of improving their students’ functioning. In Europe, physician-educators became interested in mental deficiency and began acknowledging that appropriate training could increase competency, and permit handicapped children to live normal or nearly normal lives (Landesman & Vietze, 1987).

A French doctor, Dr. Edouard Seguin, became associated with Dr. Itard and felt that much had been accomplished with Victor. On the basis of work done by Itard with Victor, Seguin believed that education of individuals with mental deficiencies could be enhanced by emphasizing the development of the sense organs (Krishef, 1983). Under the supervision of Itard, Dr. Seguin developed a comprehensive approach to educate children with mental retardation, known as the Physiological Method (Scheerenberger, 1983). Assuming a direct relationship between the senses and cognition, his approach began with sensory training including vision, hearing, taste, smell, and eye-hand coordination. The curriculum extended from developing basic self-care skills to vocational education with emphasis on perception, coordination, imitation, positive reinforcement, memory, and generalization.

19th Century

It was not until the mid 19th Century that specialized institutions existed in the sense that we know them today (Crissey & Rosen, 1986). Seguin was the first to found an educational program and school, which later became a residential institution. In 1838, at Salpetriere, France, Seguin established his educational program in a hospital for insane persons and tested his ideas for “idiots” at the Bicetre, another mental hospital (Landesman & Vietze, 1987; Scheerenberger, 1983). At Bicetre, Seguin worked with inmates with mental retardation for one year (Scheerenberger, 1983) before moving to the United States in 1848 and becoming a driving force in the education of individuals with mental retardation (Krishef, 1983).

Johann Jakob Guggenbuhl was one of Seguin’s well-known contemporaries. He referred to all retarded persons as cretins. Guggenbuhl became fascinated with this type of individual and devoted his life to the “cure” of cretinism” (Krishef, 1983). In 1839, he established a homelike institution in the Swiss Alps, called Abendberg (Krishef, 1983).

Abendberg was probably the first residential center for individuals with mental retardation. Their Guggenbuhl provided his patients with medical treatment and educational services (Krishef, 1983). The center further provided good diets, exercise, and sense training. Guggenbuhl's Abendberg was regarded as the model for institutional care and greatly influenced many in the field around the world (Kanner, 1964).

In 1842, William Twinings of Great Britain visited Abendberg and upon his return to Great Britain in 1843, created a stir with the glowing report of his findings at Abendberg. Inspired by Twining's report, the Misses White, Queen of Great Britain, started a small school with four children at Bath on the Avon, which later developed into the Rock Hall House School in 1846. In an effort to do more to care for children considered feebleminded, Great Britain created the Highgate Institution in 1848 (Kanner, 1964).

Scottish royals, Sir John and Lady Jane Ogilvy, who had had their own child with mental retardation at Abendberg, were so pleased that they established a similar experimental institution on their estate in Baldovan in Scotland in 1854. By 1867, Columbia Lodge, Scotland's first institution was established. Further, when the Census Commissioners in Ireland reported that the country had 7,033 defectives in 1861, they suggested that steps be taken similar to those in England. As a result, the Steward Institution was opened at Palerston, Scotland, in 1869 (Kanner, 1964).

An enthusiastic account of a visit to Abendberg by Herckenrath of the Netherlands in 1842 prompted the Queen of the Netherlands to make a personal journey to Guggenbuhl's show place. With the aid of the court preacher, the queen was instrumental in opening a day school for “educable “children with mental retardation on May 15, 1855. By 1857, a residential place was established in the Netherlands (Kanner, 1964).

Many more countries would follow by establishing institutions of their own. J.R. Hubertz of Denmark visited the Abendberg in 1852 and was so impressed that Denmark opened a small private institution on a farm, Gamble Bakkehus, near Copenhagen on November 1, 1855 (Kanner, 1964). A visit by Count Bombelles of Austria prompted the establishment of an institution for 300 children in Prague in 1871. Additional institutions for individuals considered to be of feeble mind would be established in Hungary, the Arbeit in 1877, in Latvia in 1854, and in Jacobstad, Finland, in 1876 (Kanner, 1964) all as a result of visits to Abendberg.

Encouraged by the work of Seguin in Paris, France, and using the model Guggenbuhl started for cretins in Switzerland, Dr. Samuel Gridley Howe became the first person to initiate institutional care for individuals with developmental disabilities in the United States (Krishef, 1983; Crissey & Rosen, 1986). This would lay the foundation of treatment methods for people with mental retardation in the United States during the 19th and 20th Centuries (Krishef, 1983).

Evolution of Institutions in the U.S.

These institutions were developed as a spin-off from those in 19th century Europe. This section will provide discussion about the evolutions of institutions and services offered in the United States.

First Institutions in the U.S.

The United States moved along in much the same manner as France did when Dr. Harvey B. Wilbur, after having visited Sequin's school in Paris, opened the first small private school for persons with developmental disabilities in Boston, Massachusetts, in 1848 (Baumeister & Butterfield, 1970). In the same year, the Massachusetts Legislature authorized an experimental school that was to be used for ten children with mental retardation. In a wing of the Perkins Institute and School for the Blind, Howe established the first public residential facility for individuals with mental retardation (Landesman & Vietze, 1987; Crissey & Rosen, 1986; Baumeister & Butterfield, 1970). Howe's program later moved to its own building in South Boston, Massachusetts, in 1855 (Landesman & Vietze, 1987) and was named the Massachusetts School for Idiots and Feebleminded Youth (Crissey & Rosen, 1986).

This American institution concentrated its efforts on trying to assist individuals with mental disabilities to function at their best possible level. It was developed to provide temporary residential placement for individuals who, after a relatively brief period of education and training, would return to community life. In New York, Dr. Frederick Backus introduced a bill at the 1846 session of the legislature for the opening of a residential school; it was passed in one house but failed to carry in the other chamber. In the winter of 1850-1851, Howe appeared before the state authorities at Albany, with some of his patients showing what he had done in Massachusetts, and pleading for the establishment of a similar school in New York. Governor Hunt of New York wrote to Howe in July 1851:

> Your visit to our capital last winter was of great service. We feel that we are much indebted to you for the success of the measure so far, and hope we may have the benefit of your experience and counsel in carrying our plan into practical operation (Kanner, 1964).

That same year, a school was opened in Albany, later moving to Syracuse, New York, in 1855 and was named State Asylum for Idiots. The school later was officially known as the Syracuse State Institution for the Feebleminded (Kanner, 1964). Pennsylvania followed next, and, on the tenth of February 1850, preliminary steps were taken to found the country's third institution of its kind. On the seventh day of April 1853, the legislature incorporated the Pennsylvania Training School for Feebleminded Children (Kanner, 1964). On April 17, 1857, an Institution for Feebleminded Youth at Columbus, Ohio, was called into existence by legislative enactment followed in 1858 by the first school for children with mental retardation in Connecticut, named the Connecticut School of Imbeciles (Kanner, 1964).

Early Education in U.S. Institutions

These early school facilities were established to serve four groups of residents on a colony plan: (1) a teachable portion for a school-attending age; (2) the practically unteachable; (3) a portion to serve adult males who had passed school-age and were not self-supporting; and (4) a portion to serve adult females who should be kept under the careful custody of the State unless they can be released under exceptionally favorable and well-guarded surroundings (Scheerenberger, 1983).

The colony plan included a training school as well as industrial, custodial, and farm departments. These schools were designed with a central building, industrial departments, and separate buildings with specially arranged dormitories and day rooms to care for residents with paralysis and profound idiocy. Other buildings were for custodial and epileptic departments, with accessories for both care and training. Provisions were made for colonizing young men, as they grew into manhood, in properly arranged houses, as farmers, gardeners, and dairy help. This approach provided the cheapest and wisest method for utilizing the labor of residents whose work would command absolutely nothing if brought into competition with even the most unskilled labor of persons of normal mind (Scheerenberger, 1983).

Expansion of Institutions in the U.S.

Early success at several schools dawned the opening of additional state-operated mental retardation facilities across the U.S. (Braddock, 1991). Kentucky opened an institution in 1860, Illinois in 1865, Iowa in 1877, Indiana and Minnesota in 1879, followed by Kansas in 1881, California in 1885, Nebraska in 1887, New Jersey and Maryland in 1888, Michigan in 1895, and Montana in 1896. Between 1848 and 1898, 24 public institutions were established and maintained by 19 states, and one by the City of New York. The total census of individuals in public institutions during this period was about 8,000 residents nationally (Kanner, 1964; Crissey & Rosen, 1986).

The South's Position on Institutional Care

The South, however, was slow in its care of people considered feebleminded. This concern over a lack of institutional facilities for people considered being of feeble mind prompted pleas for change. Many southern citizens realized the South had done little for individuals considered of feeble mind, especially compared with the North. In June 1911, a newly organized Board of Trustees of the North Carolina School for the Feebleminded met in Raleigh and accepted a bid for the city of Kinston to have an institution; later the Caswell Training School would be located there (Noll, 1995). Following the lead of North Carolina, within the next seven years other southern states opened institutions for individuals considered of feeble mind. After the Georgia Commission on Feeblemindedness reported its findings in 1918, the Georgia Legislature passed a bill that created the south's second institution (Noll, 1995). The Georgia Training School for Mental Defectives in Gracewood opened its doors to its first patients on July 1, 1921 (Noll, 1995). Between 1919 and 1923, Florida, Alabama, Mississippi, South Carolina, Tennessee, Louisiana, and Virginia all would open institutions for individuals with mental retardation (Noll, 1995).

Alabama opened the Partlow State School for Mental Defectives in Tuscaloosa in 1919; Florida opened the Florida Farm Colony for the Epileptic and Feebleminded in Gainesville in 1921; Louisiana opened the State Colony and Training School in Alexandria in 1922; Mississippi opened Ellisville State School in Ellisville in 1923;

South Carolina opened the State Training School in Clinton in 1920; Tennessee opened the State Home and Training School for Feebleminded Persons in Donelson in 1923; and Virginia opened the Lynchburg State Colony in 1914 and Petersburg State Colony in Petersburg in 1939 (Noll, 1995).

By 1921, the nation's state-operated institutions had become filled, with many states experiencing overcrowding. In many instances, institutions with a capacity to serve 350 residents were occupied by as many as 470 persons (Noll, 1995). Yet further, the number of institutions in the United States would nearly triple to 77 by 1930 (Lakin, 1979; Braddock & Heller, 1985) serving more than 100,000 persons with mental retardation nationwide (Crissey & Rosen, 1986).

Despite these gains, however, White southerners ignored the needs and concerns of their Black brethren. As the color line solidified, money for the care of Black individuals considered to be of feeble mind was not available. Black citizens considered of feeble mind involved in antisocial or criminal behavior often were adjudicated through the criminal justice system. Others, usually those causing no community problems, were placed in insane asylums or simply cared for at home by parents or relatives. Blacks in the South rarely received the possibility of achieving better opportunities (Noll, 1995).

Black patients served in institutions for the feebleminded generally followed similar patterns established throughout the South. Few southern institutions allowed integrated wards, and Black patients remained isolated in separate wings and facilities. Although ten southern states opened eleven public institutions for the feebleminded during the first four decades of the 20th Century, only two of these facilities, the Kentucky State Institute for the Feebleminded in Frankfort and the Louisiana State Colony and Training School in Alexandria, housed feebleminded residents of both races, though in segregated quarters. In addition, Virginia operated two institutions, each housing individuals of separate races. Along with its White-only Lynchburg State Colony, Virginia housed its Black citizens considered to be of feeble mind in a Black-only facility of Central State Hospital in Petersburg. This facility achieved institutional autonomy as the Petersburg State Colony in 1939, “for the purpose of caring for and training Blacks considered to have mental defects” (Noll, 1995).

Treatment in Facilities

Early 19th Century Philosophical Stance on Rehabilitation

Institutions established in these early decades had schooling and education as their objectives, and remarkably achieved success with many individuals. Between 1850 and 1880, the object was to, “make the deviant undeviant,” (Krishef, 1983); however, by the 1860s, the focus on training had shifted. The new focus was now on residents remaining as workers in expanding institutions rather than returning as productive workers of their local communities. Although the original educational function of the institution would remain prominent, once in the institution, many child-students considered to be of feeble mind would become feebleminded adult workers. Within a decade of the founding of the nation’s first schools, the educational philosophy for individuals with mental disabilities in the United States, with all its promise to train productive workers, would become a means of institutional perpetuation (Trent, 1994).

Shift in Philosophical Stance

By the 1870s and 1880s, the transformation of individuals with mental retardation to normalcy was not happening as expected. From 1870 to 1890, a growing concern existed to “shelter the deviant from society.” However, a dramatic change of alarm prevailed across the country, and the emphasis shifted from sheltering the deviant from society to protecting of society from the deviant (Noll & Trent, 2004).

It was during the late 19th and early 20th century that a number of respected leaders in the field of mental retardation produced some very unreliable research reports with no scientific findings to support the research, that retardation was a result of familial or hereditary conditions. Studies that followed supported the idea that retardation ran in families, and parents with mental retardation produced both intellectually retarded and socially deviant offspring (Krishef, 1983). These two stories represent many famous studies about the treatment of mentally retarded individual. The impact of these stories created a revolutionary way of how people mentally retarded were treated.

Jukes Story

In 1877, Richard Dugdale was first to publish such a study. This study was named the Jukes, for a family he studied that presented a high proportion of criminals and paupers that could be traced down this one family’s lineage. Dugdale visited six persons within this family’s lineage, all with different family names. He realized that all six persons “turned out to be blood relations in some degree and belonged to a long lineage, reaching back to the early colonists.” The family descended from the two sons of a backwoodsman called Max, who married two of five Jukes sisters (Kanner, 1964). This family, according to Dugdale, was noted to be "poor physical specimens with the lowest of moral standards." Dugdale concluded in his study that this was a family with a pauper history of several generations that were intermarried as to form a pauper ganglion of several hundreds. He further concluded, "retardation bred retardation" (Kanner, 1964).

Kallikak's Story

Following Dugdale's study, Henry Goddard conducted a similar study in 1912 with a family he referred to as the Kallikak's. Among their 480 descendants, 36 were considered illegitimate, 33 were considered sexually immoral, mostly prostitutes, 24 were confirmed alcoholics, and three were epileptics. Goddard concluded:

> Feeblemindedness is hereditary and transmitted as surely as any other characteristic. We cannot successfully cope with these conditions until we recognize feeblemindedness and its hereditary nature, and take care of it. In considering the question of care, segregation through colonization seems in the present state of our knowledge to be the ideal and perfectly satisfactory method (Kanner, 1964).

With additional stories of families known as the Nam family and the Hill Folks, retardation was thought to produce retardation. As a result, fear spread rampant that individuals with mental retardation would spread evil, crime, and disease if allowed to procreate (Kanner, 1964).

Eugenics and Sterilization Movement

One way of curtailing this fear was to stop the reproduction of individuals with retardation. As a result, in 1911, a group known as the Research Committee of the Eugenic Section recommended lifelong sexual segregation of individuals with mental retardation along with sterilization so they could not reproduce (Krishef, 1983). Coupled with the cry to construct more institutions, states began enacting sterilization laws. Within 50 years, nearly 30,000 individuals with mental retardation were sterilized in the United States (Davies & Ecob, 1959). Thus, people with developmental disabilities once again became outcasts, being separated from society, isolated in institutions, and sterilized without due process considerations. Fortunately, the period during which these distorted views prevailed was relatively short, approximately 10 years. Unfortunately, the distortions from this period carried over and became the foundations upon which institutional programs were built (Scheerenberger, 1983).

Introduction of IQ Testing

The original objective of institutions' founders, to establish facilities that could offer training and rehabilitation, had crumbled. In spite of gains in skills, social competence and general behavior, individuals with mental retardation were scrutinized for not showing real gains in mental ability. This was verified when the developments of methods for studying mental functions became available after 1910-1915. Two French psychologists, Alfred Binet and Theodore Simon, believed that the key to the measurement of intelligence was to focus on higher mental processes instead of on simple sensory functions. Their work on intelligence culminated in development of the Binet-Simon scale of 1905.

This metric scale of intelligence consisted of 30 items arranged in order of level of difficulty, accompanied by instruction for administration (Sattler, 1988). Henry Goddard, Director of the Psychological Laboratory at the Vineland Training School in Vineland, New Jersey, revised the test in 1908 and introduced an American version of the Binet scale test in 1910. In 1935, Edgar Doll developed the Vineland Social Maturity Scale to assess daily living skills/adaptive behavior of individuals suspected of having mental retardation. Psychologists and educators, with the development of the classification system and the intelligence quotient (I.Q.), now believed it was possible to measure and determine different degrees of mental retardation and provide appropriate training in the residential training schools (Sattler, 1988). Using these measurements, individuals were classified according to levels of severity as follows: mild retardation, intelligence quotient (I.Q.) of 55 to 69; moderate retardation, I.Q. of 40 to 54; severe retardation, I.Q. of 25 to 39; and profound retardation, I.Q. of 0 or immeasurable to 24 (DSM-IV; American Association on Mental Retardation, 2002).

Beginning of the Parent Movement

During the 1930s and 1940s, little change occurred in the way society viewed individuals with mental retardation. Within this time, the nation was in the grips of a devastating depression and, later, World War II demanded the forces of the nation, which left little time to think about programs and services for people with mental retardation (Krishef, 1983). Trends toward custodial care and warehousing increased until after World War II and throughout the 1950s (Crissey & Rosen, 1986). It was during this time that many parents of children with mental retardation became concerned about the plight of their loved ones. Beginning in the 1930s, parent groups began to form throughout the country. The first of such group was the Cuyahoga County (Ohio) Council for Retarded Children in 1933. This council operated and financed the first parent-supported community class for individuals considered “gravely” mentally impaired. Word soon spread of this group’s actions and many new groups formed in other states. In 1936, the Washington Association for Retarded Children was organized, followed a few years later by the Welfare League for Retarded Children of New York. By 1950, 88 such groups in 19 states had been established with a total membership of 19,300 persons (Scheerenberger, 1983).

Beginning of Advocacy Movement

Seven reported reasons inspired parents’ efforts to form groups: (1) evidence that institutions were limited in what they could do for children; (2) increased awareness that regular public school programs were unsuited for children with developmental disabilities; (3) the need to disseminate knowledge and information concerning mental retardation; (4) the need to challenge the validity of the finality in the words, “Nothing can be done for your child”; (5) the desire of parents to learn what more could be done for children with mental disabilities and to pursue projects on their behalf; (6) the need to strengthen the growing conviction that the responsibility is social, i.e., money should be provided for building fuller lives for individuals with mental disabilities; and (7) the realization that it was not enough spiritually just to care for one’s own child (Scheerenberger, 1983).

For the first time, parents of children with mental disabilities had opportunities to gather together and discuss mutual problems. Between 1947 and 1950, these groups met annually as delegates at a conference of the American Association on Mental Deficiency. During the conference of 1950, parents considered developing a national parent association and subsequently scheduled their first convention for Minneapolis in September 1950. From this convention, “Parents and Friends of Mentally Retarded Children” was created with the goal of promoting “the general welfare of individuals with mental retardation of all ages everywhere: at home, in the community, in institutions, and in public, private and religious groups.” Through this group’s effort, the National Association for Retarded Citizens was formed (Krishef, 1983), later assuming the title, “Association for Retarded Citizens of the United States (ARC of the United States) (Scheerenberger, 1983). Other advocacy groups would follow, such as the President's Commission on Mental Retardation (Trent, 1994). It was also during this time that the Fifth White House Conference on Children and Youth in 1950 identified mental retardation as one of two major problems affecting children in the United States. All in all, the 1940s and 1950s were very mixed periods for the nation. Fewer knowledgeable persons held old prejudices associated with heredity and crime; yet, an increasingly complex urban society often found little time for people with mental retardation (Scheerenberger, 1983).

Expansion Continues in 1950s and 1960s

The late 1950s into the 1960s righteously proclaimed the need for institutional reform both within and outside of institutions. As the National Association for Retarded Citizens (the ARC) urged a shift from custodial care, school administrators and parents uniformly were decrying the conditions at institutions, in many instances requesting change, especially in quality of life and physical environment (Scheerenberger, 1983). During this era, parents began demanding higher quality institutional care and greater opportunities for community living. Segregating individuals in large institutions, warehousing residents, and providing poor quality care became prominent civil rights issues of the time (Trent, 1994).

Despite the cries voiced by the parents' organizations and administrators, mental retardation institutions in the United States continued to grow in number and in size, often bursting at the seams (Krishef, 1983). Within the 1950s and 1960s, mental retardation institutions had swelled to 143 nationally (Lakin, 1979; Braddock & Heller, 1985). Unable to recruit and retain adequate personnel, these facilities frequently failed to provide the very rudiments of humane care. While institutional reform was in the air, alternative living environments were less available. Nevertheless, the foundation was laid for what was to come in the 1960s and the 1970s (Krishef, 1983).

Call for Institutional Reform

Kennedy's Impact

In 1961, President John F. Kennedy, became involved due to his sister's retardation. He recommended a national plan of action aimed at combating problems facing Americans with mental retardation. President Kennedy established a panel to review the condition of citizens with mental retardation. The findings would emphasize such areas as encouraging the interest of more professional workers, improving preschool programs, expanding federal funding for retardation services, increasing employment for individuals with mental retardation, and limiting institutional care to those who really needed it (Krishef, 1983). Two years later, President Kennedy initiated his plan by signing a bill that allocated federal funds for establishing a network of community centers across the country.

Decade of Legal Issues

By 1967, the nation's institutional census peaked at 194,650 residents being served in 240 state mental retardation facilities across the country (Latib, Conroy, & Hess 1984; Braddock, 1991). With constant pressure from parent advocacy groups that the custodial approach be replaced and with investigations spearheaded by President Kennedy's panel's recommendations on mental retardation of the 1960s, the period of the 1970s became the "decade of legal issues" on behalf of people with mental retardation. During that time, a number of major court decisions reaffirmed that citizens with mental disabilities had the same legal rights as any other citizen (Krishef, 1983).

One of the most influential court decisions for individuals with mental retardation of that era was the *Wyatt vs. Stickney* federal court action. This landmark class action suit in Alabama established the right to treatment of individuals living in residential institutions. Purely custodial care no longer was acceptable. The Wyatt case had far-reaching implications because it served as a basis for many other suits that were filed against institutions throughout the country (Krishef, 1983).

Deinstitutionalization and Normalization Introduced

With the advent of legal issues, the nation encountered a big push for normalized environments for its citizens with mental disabilities. Many states began embracing the concepts and practices of normalization and deinstitutionalization, which became a major force in the mental retardation field in the 1970s. This identified push toward normalized environments spurred the movement of many individuals with mental retardation from institutions to community living arrangements (also known as the deinstitutionalization movement) (Latib, Conroy, & Hess, 1984). This movement was characterized by the widely shared ideology referred to as normalization (Bellamy, Newton, LeBaron, & Horner, 1990). This theory of normalization had a great impact on the lives of people with mental disabilities, specifically with regards to the movement toward deinstitutionalization. The theory of normalization will be discussed in more detail in a section to come. With these concepts introduced nationally, deinstitutionalization and normalization became the primary objectives of President Nixon when he set a national goal of reducing institutional populations by 30 percent before the turn of the century.

Depopulation of Institutions

Success in this area was reflected between 1970 and 1979, when the number of residents in state-operated institutions decreased by 50,139 persons, though the country’s population of people with mental disabilities requiring services continued to increase

(Scheerenberger, 1983). Data on depopulation of institutions will be covered extensively in a section to come.

Legislation and Court Decisions Impacting Institutional Services for Individuals with Mental Retardation

National Legislation

Very little in the way of federal legislation relating to mental retardation existed prior to 1954. The first legislation to establish special schools for people with mental disabilities was enacted in a bill sponsored by Senator Frederick Backus of New York in 1848 leading to the erection of New York State Asylum in 1851.

In 1927, the U. S. Supreme Court in *Buck v. Bell* ruled that forced sterilization of people with disabilities was not a violation of their constitutional rights. The decision removed the last restraints for eugenists, who advocated that people with disabilities be prohibited from having children.

In 1954, the U. S. Supreme Court in *Brown v. Board of Education of Topeka* ruled that separate schools for Black and White children inherently are unequal and unconstitutional. This pivotal decision became the catalyst for and inspiration of the disability rights movement. This ruling pushed people with disabilities to fight for their equal rights. In that same year, *Public Law 83-531*, titled, *The Cooperative Research in Education Act*, was enacted. This legislation provided federal funding for educational research on individuals with mental disabilities and enabled them to receive funds for studies in this area (Krishef, 1983).

The first federal legislation directed specifically at providing services for people with mental disabilities was passed in 1958 as *Public Law 85-926*. This piece of legislation authorized federal funds to universities for training mental retardation specialists (Krishef, 1983; Scheerenberger, 1983).

Besides federal legislation, another legal method used most effectively by those interested in helping individuals with mental disabilities has been the class action lawsuit. This type of lawsuit was used with dramatic effectiveness for many different groups of individuals with mental disabilities during the decades of the 1960s and 1970s, leading to several landmark decisions that were used to establish the rights of people with mental disabilities (Krishef, 1983). One of the first lawsuits filed to protest conditions inside a residential institution was the case of *Rouse v. Cameron* of the 1960s. Rouse had been committed involuntarily to a mental hospital in the District of Columbia because he had been found guilty of carrying a dangerous weapon. The lawsuit claimed that, because he had been sufficiently ill to be committed to an institution, he was entitled to treatment that would restore his well being so that he could be released from institutional care. The court held that a person involuntarily committed had a right to treatment, and it mandated that all persons committed to public institutions (including those with mental retardation) should be provided with habilitative and restorative treatment (Krishef, 1983).

During the 1970s, federal courts took major interest in mental retardation institutions, declaring many of their conditions and procedures unconstitutional (Scheerenberger, 1983). The first such class action case, related to the constitutional rights to treatment of institutionalized residents, was the *Wyatt v. Stickney* class action suit of 1972 (Scheerenberger, 1983). Heard in Alabama in 1971 and 1972, this case, brought against the Alabama Department of Mental Hygiene by the guardian of Ricky Wyatt and aggrieved employees when budget cuts reduced their already sparse ranks (Baumeister, 1982; Cavalier & McCarver, 1981), sought to establish constitutional rights of residents of institutions to receive constructive treatment that included an individualized program, a humane physical and psychological environment, adequate and qualified staff, and programs provided in the least restrictive manner possible (Krishef, 1983). In this case, the family and employees argued that patients were denied proper treatment because of staff reductions. Judge Johnson of the District Court of Alabama declared the constitutional rights of persons residing in institutions serving those with mental disabilities in Alabama were being violated (Scheerenberger, 1983).

A second-class action lawsuit impacting the field of mental retardation involved due process. The *Lessard v. Schmidt* decision of 1972 declared Wisconsin's state statutes to be unconstitutional, since existing procedures failed to guarantee rights of due process. Anyone deemed in need of residential treatment had the right to a trial, at which time his or her interests would be represented and the need for institutionalization would be challenged (Scheerenberger, 1983). A third class action case was filed in New York in 1972. *The New York State Association for Retarded Children v. Rockefeller* focused on Willowbrook State School, charging widespread physical abuse, inhumane and destructive conditions, overcrowding, poor staffing, long periods of cruel and torturous solitary confinement, and practically no treatment to help residents prepare for return to community living. While the court did not uphold the residents' right to treatment, it did rule that residents with mental disabilities had a constitutional right to be protected from harm, based on the eighth amendment to the U.S. Constitution (Krishef, 1983).

In 1973, the issue of involuntary servitude came under review. In the class action lawsuit, *Souder v. Brennan*, brought against the U.S. Department of Labor, sought to enforce provisions of the *Fair Labor Standards Act* of 1966 relative to resident workers and residential facilities for both persons with mental illness and mental retardation. The court in this case held that the minimum wage, overtime, and other provisions of the *Fair Labor Standards Act* applied to people with developmental disabilities residing and working in residential facilities. This decision was subsequently overturned however; the precedent was established that residents were no longer to provide free labor (Scheerenberger, 1983).

In another banner class action court case, *Halderman v. Pennhurst* (1977), the court ruled, "People with mental disabilities in large institutions suffer from apathy, stunted growth and loss of Intelligence Quotient (I.Q.). The courts felt that the smaller the living unit in which an individual lived, the higher the level of behavioral functioning." This case, actually initiated in 1974, because of what were thought to be harmful results encountered by residents residing at Pennhurst State School, sought to phase out and encourage closure of institutions in favor of suitable community living arrangements for all residents with mental retardation in Pennsylvania (Griffith, 1986). The court further ruled that 14th Amendment rights to equal protection for individuals with mental disabilities residing at Pennhurst were being violated. Since isolation and confinement of residents to Pennhurst were counterproductive to habilitation, the judge concluded, “Pennhurst should be regarded as a monumental example of unconstitutionality with respect to habilitation for individuals with mental retardation” (Krishef, 1983).

Moreover, 1974 witnessed the filing of additional class-action lawsuits on behalf of individuals with mental disabilities. The class action suit of *Welch v. Likens* filed in Minnesota on behalf of a group of institutionalized residents, asked the court to remove these residents from Minnesota’s institutions for the retarded. The court agreed and held that committed residents had constitutional rights to adequate care and treatment to help restore or improve mental functioning. The judge further ordered state officials to make every effort to place individuals with mental disabilities into the best possible, least restrictive settings, taking into consideration physical and mental conditions (Krishef, 1983).

Moreover, the class action case, *Wuori v. Zitnay* of 1978, provided a landmark court decree that protected civil rights of individuals with mental retardation in Maine helping prevent unnecessary institutionalization of persons with mental disabilities who can live in community-based settings. This ruling recognized rights of residents formerly institutionalized to receive “habilitation including medical treatment, education training, and care and treatment in community settings as well as for those who remain institutionalized (Krishef, 1983).

Subsequently, since civil rights litigation and class action lawsuits had been two of the primary vehicles through which people with mental disabilities had been able to obtain democracy (Hayden, 1998); laws were enacted to ensure that violations of residents' federal rights related to conditions of confinement would be monitored. Acts such as the *Fair Labor Standards Act* of 1973 helped provide fair wages for working labor residents residing in state institutions. This meant, beginning in 1974, minimum wages must be paid to residents living in facilities who performed work of consequential economic benefit to the institution (Gaver, 1975). The passage of *Public Law 94-142*, the *Education of All Handicapped Children Act* of 1975 held the strongest position regarding rights to education for every child with mental disabilities. This federal legislation mandated educational systems to provide all students' with specific disabilities a free and appropriate education, in a setting that would, "to the maximum extent appropriate," allow interaction with regular education students (least restrictive environment, or LRE), governed by a written, individualized education program (IEP), and be based on a thorough evaluation of the students needs (Scheerenberger, 1983; Huefner, 2000). In 1990, this Act was renamed the *Individuals with Disabilities Education Act* (IDEA). In 1980, the *Civil Rights of Institutionalized Persons Act* (known as CRIPA) was enacted to investigate state operated facilities for violations in care and services (U.S. Department of Justice, 1999).

The latest in a series of civil rights laws protecting groups with developmental disabilities from discrimination was *The American with Disabilities Act* (ADA) of 1990. Under ADA, private employers and commercial enterprises serving the public are obligated not to discriminate against those with disabilities with regard to maintaining a job and providing services (Huefner, 2000).

This act spawned the case of *Olmstead v. L.C.* of 1999, and a Supreme Court ruling of Title II of ADA, which required all states to provide services, programs and activities developed for residents with disabilities in the, “most integrated settings appropriate to meet the needs of qualified individuals with disabilities.” Specifically, the Supreme Court decided that all states were obligated to place qualified individuals with disabilities in community settings, rather than institutions, when treatment professionals determined that a community placement reasonably could accommodate the person, taking into account resources available (Lakin, 2002).

Most recently, the *Developmental Disabilities Assistance and Bill of Rights Act*, of 2000 found that “disability does not diminish the rights of individuals with developmental disabilities to live independently, to exert control and choice over their own lives, and to participate fully and contribute to economic, political, social, cultural, and educational mainstream of society” (Lakin, 2002).

Changes as a Result of Legislation

These legislative acts and class action lawsuits were instrumental in changing the landscape of the United States’ philosophy on how people with mental disabilities would be served in the future. Addressing numerous complaints alleging violations of due process rights and equal protection, the country became committed to equal protection under the law for the developmentally disabled. This meant ensuring that a quality assurance system designed to address problems of abuse and neglect and inadequate treatment was in place (Hayden, 1998).

With the courts stepping in and taking action, the focus changed to removing the dehumanizing features of institutional programming. Various court rulings held that (1) each individual with mental retardation had a right to an individualized treatment and training program in the least restrictive environment; (2) public institutions were responsible for preparing the individual for return to community life; (3) standards had to be developed to upgrade the quality of residential services; (4) school-aged children with mental retardation were entitled to a free appropriate education using publicly supported funds; (5) access by individuals with mental retardation to vocational training programs, from which they had previously been excluded, had to be facilitated; (6) equal employment opportunities be applied to qualified individuals with mental retardation; (7) rights of institutionalized residents to be paid for work be ensured; and (8) protection of legal rights of citizens with mental disabilities be safeguarded (Krishef, 1983). The courts further viewed individuals residing in a public institution as being in the most restrictive settings possible for a person with a mental disability (Krishef, 1983). Consequently, courts argued that, “unjustified isolation or segregation of qualified individuals with disabilities through institutionalization was a form of disability-based discrimination” (Lakin, 2002).

These rulings spawned the nation to become further committed to a community-based alternative initiative for individuals with disabilities (Lakin, 2002). This national commitment was credited for a greater push for institutional reform, which included closure or deinstitutionalization of state-operated institutions (Anderson, Prouty, & Lakin, 1999; Hayden, 1998). Between 1967 and 1980, statistics showed that the total population in large state institutions had declined steadily (Bruininks, 1990). For example, the numbers of individuals served in state institutions decreased from 194,650 to 128,550 (Best-Sigford, Bruininks, Lakin, Hill, & Heal, 1982; Scheerenberger, 1976). During the three decades between 1970 and 2000, state institution populations decreased from 186,750 average daily residents to 47,500 average daily residents. This equated to an average decrease of 46,450 individuals served in institutions per decade (Lakin, Smith, Prouty, & Polister, 2001). Similarly, first admissions had also declined from 7.8 per 100,000 populations in 1965 to 5.4 in 1971, and to 2.7 in 1979 (Lakin, 1979).

By 1988, the percentage of individuals served in large congregate settings had dropped nearly 60 percent, from 194,650 in 1967 to 91,000 (Braddock, 1990). Every state decreased its average daily population, with the largest decreases occurring in New York (-5,606), California (-2,896), Pennsylvania (-1726), Massachusetts (-1,625), Texas (-1585), and New Jersey (-1,447) (Lakin, Smith, Prouty, & Polister, 2001).

In five-year periods, state institution populations decreased by 16.4% between 1980 and 1985, 23.2% between 1985 and 1990, 24.4% between 1990 and 1995, 24.9% between 1995 and 2000, and 15.5% between 2000 and 2005. Between 2000 and 2005, every state operating one or more large state facilities decreased its institutional populations, with decreases of more than 40% in Alabama, Delaware, Indiana, and Nevada (Coucouvanis, Lakin, Prouty, & Webster, 2006). This all was due largely to the implementation of aggressive community service initiatives involving funding of small community-based group homes, in home family support programs, and specialized work programs (Braddock, 1991). Since the 1990s, more than 12,000 supervised small community-based group homes exist, which house 15 or fewer residents with mental retardation in the United States (Braddock, 1991).

Since 1970, as reported by Braddock (1991), 22 states have closed or scheduled closure of 60 state institutions serving individuals with mental disabilities. Similarly, there were 76 fewer institutions operating in 2000 than in 1991. During the decade, nine states closed the last of their state institutions (Lakin, Smith, Prouty, & Polister, 2001). As part of these trends, seven closures of state institutions occurred in 2005 with an annual average of 3.5 closures between 2000 and 2003 and 5.5 closures in 2004-2005 (Coucouvanis et al., 2006). This is one-fourth of the total number of institutions that existed in 1970 and accounted for more than three-fourths of state school closures within the past 10 years.

These numbers reflect the practical reality that the availability of institutions for families of individuals with mental retardation has become less of an option (Latib, Conroy, & Hess, 1984). By the same token, the development of community-based group homes for people with mental disabilities has increased at a rate that parallels the decrease in the number of individuals served in large state facilities (Bruininks, 1990; Hill, Lakin, & Bruininks, 1984).

Historical Overview of the Origin of Institutions in Texas

Evolution of Institutions in Texas

One of the earliest references related to services to people with mental disabilities in Texas appears in an 1858 law outlining procedures for admitting patients to the Austin State Lunatic Asylum, opened in 1861. Section 12 of the document read: “No idiot who can be safely kept in the county to which he belongs shall be sent to the Asylum” (Gaver, 1975).

In 1899, the 26th Texas Legislature authorized its first services specifically for individuals with mental retardation. Individuals with mental disabilities would be served in a unit of the Abilene Epileptic Colony when the 27th Legislature established it in 1901. It wasn’t until 1915 that the Texas Legislature passed House Bill 73 to establish the state's first facility exclusively for people with mental retardation. Many of the facility’s residents had been housed at the Austin State Lunatic Asylum until then. Two years later, the State Colony for the Feebleminded opened on Austin's outskirts with an initial admission of 65 females, ranging in age from six to 49. All residents admitted were required to have an IQ of 80 or less with special preference to students within the ages of six to 21. From its inception, the State Colony for the Feebleminded faced major shortages. The school faced a lack of dormitory space and lacked personnel trained in the field of mental retardation. Other shortfalls included funding to expand facilities to meet the school’s needs and purchase equipment designed for training in this type of school (Gaver, 1975).

In 1919, the Texas Legislature abolished the colony's original board of managers and replaced it with a State Board of Control. By 1925, the Abilene Epileptic Colony was renamed Abilene State Hospital, although the hospital continued to treat people with epilepsy exclusively. The same year, the State Colony for the Feebleminded was renamed Austin State School, and, by 1927, an on-site building for academic and vocational training had been added to the facilities and more capable residents were assigned by sex to domestic or farming chores. In 1933, the Texas Legislature appropriated $92,000 in unexpended funds of Austin State School to purchase more land east of Austin for a farm colony for feebleminded adult men (Gaver, 1975). In 1934, male residents of Austin State School were moved to the school's new farm on the eastern edge of Travis County. At this institution, named Austin State School Farm Colony, the residents would perform dairy, poultry, and truck farming (TDMHMR Public Information Office, 1989).

Texas’ need continued for residential facilities and, because of this need, additional schools were built. Mexia State School, originally a German prisoner-of-war camp during World War II, was opened in 1946 as the state’s third school to serve individuals with mental retardation (Gaver, 1975; TDMHMR Public Information Office, 1989). Originally intended as a home for senile women, transferred there from overcrowded state hospitals, by 1951, it housed women, men, and boys and girls all with mental retardation. By 1946, residents’ census in Texas state schools numbered almost 3,000 with more facilities needed. In 1949, the Legislature established a nine-member Board of Texas State Hospitals and Special Schools appointed by the governor. The

Board assumed responsibilities for management of the Abilene State Hospital complex that consisted of 30 wards and numerous associated buildings (TDMHMR Public Information Office, 1989). It also allowed the hospital to begin admitting Black patients, but none actually were admitted until the completion of two Black wards in 1952. The State Hospital was renamed Abilene State School in 1957 (Gaver, 1975).

Changing Philosophical Stance in Texas

The post-World War II period witnessed changing treatment philosophies for expanding populations of individuals with developmental disabilities. This new philosophy encouraged a shift from custodial care in isolated settings to social, occupational, and life-skills training for preparation for community integration. Administrators of Texas schools between the 1950s and 1960s worked to improve the facilities and programs for residents (Gaver, 1975).

For instance, in November 1951, all men at Mexia State School were transferred to the newly formed Texas Confederate Home at Mexia and, by 1958 all men at Mexia State School had been transferred to other institutions with exception of its school-aged population. Now known as Mexia State School, it became one of the first schools to be selected by the Texas Education Agency to establish a vocational rehabilitation program for individuals.

Due to a continued need to combat overcrowding, Denton State School was authorized by the Legislature and built on land purchased with funds donated by Denton County citizens in 1960. Lufkin State School would follow, opening in 1962 after its conversion from a U.S. Air Force radar base. One year later, Austin State School Farm

Colony would become an independent facility, renamed Travis State School (Gaver, 1975).

Despite changes of the early 1960s, the need for additional state schools in Texas continued through the decade. Texas began to experience an ever-expanding waiting list of parents requesting services in state schools for their children with mental disabilities. As a result of the growing need for services and in an attempt to reduce the list of applicants waiting for placement in state schools, five additional schools were opened. The Texas Legislature authorized construction of Southwood State School, which opened in 1968, and established Lubbock State School and San Angelo Center, which opened their doors in 1969. In 1970, Corpus Christi State School was opened, and in 1974, Brenham State School opened. In 1975, the Texas Legislature authorized San Antonio State School, and, in 1976, Fort Worth State School was opened to serve residents (Gaver, 1975).

Legal Issues in Texas

With the establishment of additional state-operated schools, Texas served roughly 10,000 residents in state schools. Along with school expansions and an ever-expanding waiting list for placement, a change evolved related to the care and treatment philosophy within the state (Gaver, 1975).

In November 1974, a lawsuit was filed in Tyler at the U.S. District Court for the Eastern District of Texas against the Commissioner and other TDMHMR officials. This class action suit was filed by a group of people including the family of John Lelsz, a former client of the Austin State School. The *Lelsz v. Killian* (later renamed *Lelsz v.*

Kavanagh) class action suit was filed on behalf of people with mental retardation to protect their civil rights and to seek changes and improvements in the system. This lawsuit, which sought relief not in the form of punitive damages, but of chronic abuse and neglect, inadequate training, institutionalization, and failure to expand community services, would prove to be one of the most important court rulings on behalf of people with mental retardation in Texas history (Vargas, 1987).

Throughout the 1980s and 1990s, Texas followed the nation’s trend by embracing normalization and deinstitutionalization concepts and emphasizing its care and treatment options in the community. As a result, TDMHMR began allocating large amounts of its general state revenue and federal funds to community providers and placed a greater emphasis on downsizing state-operated mental retardation facilities. In spite of these national gains in facility reduction and downsizing, the appropriateness of institutions as a treatment modality nevertheless continued to be questioned.

Legislation and Court Decisions Impacting Institutional Services for Individuals with Mental Retardation in Texas

Legislation and Court Decisions in Texas

Texas laws related to individuals with mental retardation in Texas began in 1963, when the Texas Legislature passed the *Federal Mental Retardation Facilities and Community Mental Health Centers Construction Act*. This Act provided matching grants to Texas for construction of community MHMR centers (TDMHMR Public Information Office, 1989).

In the same year, citizen-planning groups were appointed to survey the state’s mental health and mental retardation needs, influencing passage of the *Texas Mental Health and Mental Retardation Act* of 1965. The same year, the Texas State Legislature lobbied for the establishment of the Texas Department of Mental Health and Mental Retardation (TDMHMR) and abolished its previous Board for Texas State Hospitals and Special Schools. The new department's mission was to offer an array of services responding to the needs of individuals with mental illness and mental retardation, enabling them to make choices resulting in lives of dignity and increased independence (Braddock, 1991). The department's role was narrowed exclusively to mental health and mental retardation services from its previous incarnation of services for Texans with tuberculosis, orphans, and individuals who were blind and deaf. It also authorized county-based training centers for persons with mild or moderate developmental disabilities (Gaver, 1975).

Under the new TDMHMR, habilitation programs were designed to enable individuals with disabilities to function in mainstream society and to enter the job market. This new program further emphasized outpatient treatment, outreach and counseling services, recreational programs, vocational workshops, and special education courses with the use of long-term institutionalization as a last resort. Yet, despite great intentions, overcrowding and understaffing in Texas’ state institutions persisted (Gaver, 1975).

Also, in 1974, Texas was involved in two lawsuits filed by Dallas Legal Services on behalf of patients and residents of facilities. *Jenkins v. Cowley,* filed in April 1974, alleged that state hospitals failed to provide adequate treatment in the least restrictive environment possible. The second lawsuit, which was the landmark case for mental retardation in Texas, sought to create changes in its mental retardation facilities. Known as *Lelsz v. Killian* class action lawsuit, eventually renamed *Lelsz v. Kavanagh*, filed in November of 1974, sought to improve conditions at state schools as well as to create greater community placement opportunities for individuals with mental retardation (Vargas, 1987; Braddock, 1991; Gaver, 1975). The conditions of the *Lelsz* settlement required the Texas Department of Mental Health Mental Retardation to provide residents of state schools with least restrictive alternative living conditions and accessibility to quality medical and dental services. The settlement also guaranteed against physical and emotional abuse and neglect, guaranteed against administering medication as punishment, provided for adequately trained and qualified staff, and provided a safe and clean environment. In 1991, a final settlement was reached and, under the agreement, the initial suit would be dismissed when the first of two state schools was closed and 600 individuals placed in community living arrangements (Jones & Allee, 2002).

Changes in Texas as a Result of Legislation

For Texas, both through policy direction and court rulings stemming from the *Lelsz v. Kavanagh* class action lawsuit, the TDMHMR system began downsizing its state school population. In 1992, Governor Ann Richards approved the closure of Fort Worth State School and Travis State School in Austin by 1998; both schools was closed (Jones & Allee, 2002).

Data for Texas revealed that between the periods from 1977 to 1988, the annual average number of residents served in state residential facilities declined from 10,843 to 7,662 (Braddock & Mitchell, 1990). Additionally, between the period of 1990 to 2000, the annual average number of residents served in state residential facilities declined from 6,978 to 5,393 (Lakin, Smith, Prouty, & Polister, 2001). By 2005, data for Texas reported that the total state institution enrollment for individuals served in its 13 state schools was 4,977 a significant decrease served in state mental retardation institutions over a 29-year period (Coucouvanis, Lakin, Prouty, & Webster, 2006). By the same token, the total number of community-based residential placements increased within this period, with more than 1,500 individuals being placed (Braddock & Mitchell, 1990). Important to note, since the dismissal of the *Lelsz* class action suit, no additional state schools have closed or are slated for closure in Texas. Texas continues to rely largely on congregate institutional settings for 86 percent of its out-of home placements (Braddock, 1991). Presently, Texas ranks poorly compared to other states in its efforts to reduce its population served using the traditional large institutional model of care. Of the 50 states, Texas currently ranks 48th ahead of only Mississippi and Oklahoma using this model of care. This ranks poorly to the nation’s most populous states in terms of the percentage of total expenditures committed to community services versus that spent for congregate institutional care (Braddock, 1991). In contrast, Texas ranks first in percentage of total spending allocated to congregate state school settings, and last in allocations for community services (Braddock, 1991).

Normalization, Family Member Perceptions and Factors for Placement

This combination of normalization, deinstitutionalization, family member perspectives, and factors influencing placement provides the framework for this particular study. This section will provide background information on the concept of normalization and its impact on future placement considerations for family members' of people with mental disabilities.

Introduction of the Normalization Theory

The normalization theory first came to the United States from the Scandinavian countries in the late 1960s. The theory, promoted by Nirje (1969) and Bank-Mikkelsen (1969), involved "making available to individuals with mental retardation, patterns and conditions of every day life which are as close as possible to the norms and patterns of mainstream of society" (Nirje, 1969). According to Nirje (1969), normalization was based on the idea that all individuals have the right to experience a "normal" rhythm to their day (e.g., get up in the morning, go to bed at an age-appropriate time), to their life (e.g., school, work, interpersonal relationships), and to their year (e.g., vacations, holidays). According to Wolfensberger and Tullman (1991), people with disabilities are often "devalued" and are typically a) segregated from society, b) group with other "devalued" people, and c) served by less competent workers than "valued" people. They stated:

> Normalization requires that a devalued person or group have the opportunity to be personally integrated into the valued social life of society. Devalued people would be able to live in normative housing with the valued community and with

> valued people; be educated with their non-devalued peers; work in the same facilities as other people; and be involved in a positive fashion in worship, recreation, shopping, and all other activities in which the member of society engage. (213).

Bank-Mikkelsen suggested that, in order to "normalize" their lives, individuals with mental retardation should live in their natural surroundings. Therefore to implement the concept of normalization, efforts were made to integrate individuals with mental disabilities into the community and help them fully use their abilities no matter how limited those abilities may be. Individuals with mental retardation were recognized to have a basic right to receive the most adequate treatment, training and rehabilitation available (Bank-Mikkelsen, 1969). In other words, normalization, as a philosophy, applied the practices of providing lesser restrictive alternatives. The introduction of this concept spurred the movement known as the deinstitutionalization movement (Latib, Conroy, & Hess, 1984).

Deinstitutionalization encompassed three interrelated processes: (1) prevention of admission by finding and developing alternative community methods of care and training; (2) return to local communities of all residents who had been prepared through programs of habilitation and training to function adequately in appropriate local settings; and (3) establishment and maintenance of a responsive residential environment which protects human and civil rights and that contributes to an expeditious return of individuals to normal community living whenever possible (Scheerenberger, 1983). At that time, many people felt that placement in community settings was most appropriate because institutional care was becoming obsolete and inappropriate (Grob, 1995).

Family Members' Perceptions of Institutional Placement

Family members have however, shared mixed views about placement options. While many embraced the concepts of normalization and deinstitutionalization and elected to move their family members with mental retardation into community settings, others have not been so excited about the concepts.

The movement toward deinstitutionalization, coupled with the concept of normalization, not only created controversy but also had been a firestorm in the field of mental retardation for many years. Though many advocated closing all institutions, the primary purpose was "to habilitate as many as possible for community placement (Scheerenberger, 1983). Despite the acceptance of the deinstitutionalization philosophy by professionals, parents, and program planners, not everyone was or is caught up in the fervor of the movement (Novak, 1976).

Early Views of Family Members

The earliest look at parents' perceptions toward placement occurred in 1953, when Pacific Colony State Hospital initiated its community care program. At that time, placement personnel confronted two problems: (1) community resistance and (2) the fact that potential foster parents wanted to serve only younger children or those with no obvious developmental anomalies or physical handicapping conditions. Foster parents also were not willing to accept such a responsibility of caring for this population for a nominal fee (Scheerenberger, 1983).

Parents objected to the community care initiative for a variety of reasons. Many reported: (1) the patient was happy in the institution, has friends on the ward, and needed medical supervision which only the institution could provide; (2) prior to commitment, many resided in private or county boarding homes and these were highly unsatisfactory; (3) the outside world is cruel to individuals with mental disabilities, whereas institutions understand them and are kind; (4) proposed community homes are operated by families or unacceptable racial or religious grouping; (5) patients might escape from the community-based homes and be killed; (6) they waited a long time to advance up the waiting list, and now just as they have fully accepted their child being institutionalized for life, the question of placement is raised all over again (Trent, 1994).

Additional Views of Family Members

Several studies were completed nationally since the late 1970s related to perceptions of parents toward institutionalization of their relatives with mental retardation. In one of the earliest studies, Klaber (1969) surveyed parents of people in institutions in Connecticut. In his research, Klaber found that more than three fourths of parents surveyed believed that institutions in which their family member resided were extremely high quality. He concluded that, "The parents were convinced of the excellence of the facilities in which their family members were placed. The praise lavished on the institutions was so extravagant as to suggest severe distortions of reality in this area."

Brockmeier (1975) reported similarly high levels of satisfaction, coupled with skepticism about community-based care, among families of people with mental disabilities in Nebraska institutions. Willer, Intagliata, and Atkinson (1979) reported overwhelming satisfaction among families of institutionalized people in New York State. Further, Meyer (1980) surveyed parents of 273 residents in Wester Center, an institution in Western Pennsylvania, on their attitudes toward continued institutional placement versus potential placement in a community residence. Meyer found that more than 70 percent of parents were satisfied with the care and services provided by the facility. When questioned about small group homes, the parents were opposed to the idea of community placement and thought that remaining in the institution would be best for their relatives.

In another study, Conroy (1984) surveyed families of 1611 people living in institutions in Pennsylvania who had been “nominated” for movement to the community. No fewer than 91 percent of these families reported being “satisfied” or “very satisfied” with institutional services, and 81 percent were “opposed” or “very opposed” to the idea of community placement. Conroy (1987) further found that 72 percent of the families of residents at the Georgia Retardation Center reported being “very satisfied” with services provided to their relatives and overwhelmingly opposed the idea of movement to community services.

Further, Payne (1976) surveyed parents of residents in Texas institutions and found that, while they were not opposed in principle to the option of small community–based group homes, they still preferred the institution. Additionally, Payne’s research was first to identify a “deinstitutionalization backlash” among parents/caregivers of residents in state-operated institutions for the mentally disabled. Payne characterized the backlash group as a loosely knit counter-movement of various local and statewide associations of parents organized in support of institutions as opposed to community residential facilities. His study consistently reported high satisfaction with institutions among families who have placed relatives there (Janicki, Krauss & Seltzer, 1988). While many parents saw community living arrangements as a viable way to meet the residential care needs for some individuals with developmental disabilities, it is well established that parents of most individuals residing in large institutions had a distinct preference for that type of residential facility (Atthowe & Vitello 1982; Frohboese & Sales, 1980; Payne, 1976). However, according to Roos (1976), “the residential institution for people with developmental disabilities is in danger of emulating the dinosaur if it does not undergo adaptive modification in response to the rapid changes occurring in the field of mental retardation.”

Factor’s Influencing Placement

Parents deciding to request placement of their family members with mental disabilities (Blacher, 1990) were influenced by numerous factors. Most often it was related to family stress, characteristics of the person with the handicap, and the availability of caregiver support (Sherman & Cocozza, 1984). In many instances, family members reported requesting placement because of greater problems in dealing with the general care and supervision of the mentally disabled person (Black, Cohn, Smull & Crites, 1985; Black, Molaison, & Smull, 1990; Wolf & Whitehead, 1975). Persons placed out of the home tended to have more severe disabilities, greater medical or physical care needs, fewer functional skills (Borthwick-Duffy, Eyman, & White, 1987;

Eyman, O'Conner, Tarjan, & Justice, 1972; Sherman, 1988), and high levels of maladaptive behavior (Black et al., 1985; Hobbs, 1964; Shellhaass & Nihira, 1969; Sherman, 1988).

Early advice from professionals and friends has been contradictory. Gorham (1975) pointed out that professionals told parents often, to institutionalize their child with mental disabilities. These professionals usually assumed that the majority of parents of individuals with developmental disabilities supported the concepts of normalization and least restrictive environment for their offspring. This inference is based, as least in part, on the behavior of those outspoken parents active in advocate groups and who initiated litigation ensuring that these principles were incorporated into their children's treatment program (Meyer, 1980). It is possible, however, that this vocal minority is not representative of the silent majority? A study by Ferrara (1979) found that there was discrepancy between what parents think and what professionals think that parents thought. Subsequently, what was popular opinion several years ago may not be popular opinion today (Frohboese & Sales, 1980). Stedman (1977) suggested that deinstitutionalization of a relative with a developmental disability represents stress because it forces the family to question whether institutionalization is, or ever was, appropriate. The crisis of the deinstitutionalization decision parallels the crisis of the situations faced earlier by the family-diagnosis, burden of care, and institutionalization (Willer, Intagliata, & Atkinson, 1979).

A study by Frohboese and Sales (1980) reported that families in Nebraska believed the state institution offered greater freedom of movement, independence, and safety. The greatest concern expressed by these families about deinstitutionalization was their perception of the lack of permanence of community settings. Other concerns addressed by parents included availability and quality of supervision, care, and other resources; many families believe that their relative needs 24-hour medical care and felt this would not be provided in the community (Atthowe & Vitello, 1982; Frohboese & Sales, 1980; Meyer, 1980). Payne (1976) found that parents were in favor of maintaining the institution and were skeptical of the advantages of small group homes. Parents agreed fairly strongly that large institutions offered the advantages of a concentration of mental retardation expertise, opportunities for people to be with persons like themselves, and an opportunity for them to be protected from the stressors of community life. Lastly, parents believed that large institutions were the tried and true way of caring for individuals with mental disabilities and that those institutions would be there long after they died (Payne, 1976).

CHAPTER III

METHODOLOGY

The purpose of this study was to identify and describe variables influencing family members' decisions regarding continued placement of family members with mental disabilities in one state-operated institution.

To respond to the purpose, four research questions were addressed:

1. What variables do family members use to seek initial placement of family members with mental disabilities in state-operated mental retardation institutions?
2. What variables do family members use to maintain placement of family members with disabilities in state-operated mental retardation institutions?
3. How do family members assess the quality of services provided in a state-operated institution?
4. To what extent do personal support variables (emotional, financial, social, physical/health and facility) impact family members' decision to maintain institutional placement?

This information will be helpful to clinicians and parents faced with difficult decisions of whether or not to continue institutionalization of a family member with a mental disability.

Research Design

The research design applied in this study was a correlational research design, which is appropriate when analyzing causal relationships among three or more variables in a single study and to predict scores on one variable from research participants' scores on other variables. The advantage of the correlational research design is that it allows the researcher to determine not only whether a relationship exists between variables, but also the degree of the relationship. A correlational research design allows analysis of variables, either singly or in combination, that affect the pattern of behavior (Gall, Gall, & Borg, 2003).

This design is preferred because experimental manipulation of variables is not needed in this study. Since the researcher chose to study only family members of residents with mental retardation residing in one state-operated institution that had the capabilities to move into a community-based setting, purposive sampling was used to obtain information relevant for the study. The advantage of purposive sampling is that it allows the researcher to select individuals who are likely to be "information rich" with respect to the purpose of the study (Gall, Gall, & Borg, 2003).

Population

The population for the study was family members of adults with mental retardation receiving services in one state-operated mental retardation institution, as identified by the Southwood State School Daily Census Report. This sample was selected because the researcher desired to study a group of family members facing similar decisions regarding maintaining continued placement of a family member with a mental disability in one state-operated mental retardation institution (i.e., Southwood State School). Also, the researcher looked at family members that had a relative with a mental disability placed in a mental retardation institution located in the same geographical location (i.e., Southwood, Texas).

Southwood State School.

For the purpose of this study the proxy name Southwood State School was used in place of the actual name of the State School used in the study. The institutional setting (Southwood State School) was opened in April 1968 as a state school facility of the Texas Department of Mental Health and Mental Retardation. The school, located on a 242-acre site on a bend of the Brazos River north of Southwood, was constructed in phases, with the first phase to provide accommodations for 500 students. The first 450 residents were admitted in April 1968. The school serves adults in a fifteen-county area along the Gulf Coast from Orange County to Matagorda County. Residents are assigned to seven units in eleven buildings, depending on the severity of their mental disability.

Some of the services offered at Southwood State School include a comprehensive, on-campus, residential and vocational programming on a 24-hour, 7-day-a-week basis. This institution also offers a range of residential and vocational services, with instruction in areas of academics, personal care, social skills, home management, and recreational skills.

Additionally, the school offers an intensive physical-therapy program daily including the Russell Shearn Moody Riding Arena, the Reva Williams Petting Zoo, and the Jesse H. Jones Wing of the Rehabilitation and Therapeutic Center. The result is one of the most comprehensive hippotherapy (physical, speech, and occupational therapy using horses) programs in the Southwest. Southwood State School in 1994 was the fourth largest employer in Fort Bend County. Expanded medical, dental, behavioral, and recreation programs have also improved the basic care of the residents of the school.

Southwood currently serves approximately 500+ adults diagnosed as having mild, moderate, severe, and profound mental retardation. This setting serves adults with mental retardation who may have additional disabilities including mental illness and other emotional disorders, behavioral disorders, physical disabilities, seizure disorder, cerebral palsy, autism, and other developmental disabilities.

Participants

Fifty-one family members of adults with mental retardation who receive services from Southwood State School participated in the study. Family members of residents living in the institution were asked to participate in this study. The family members selected had a family member with a mental disability who had the capability to move into a community-based setting. The primary selection criteria for these participants was that they were familiar with the sample members with mental retardation, and that they were comfortable responding to questions regarding both these individuals and themselves. Family members in this study, also referred to as caregivers, consisted primarily of mother, father, brother, sister, aunt, uncle, and cousin who had a current history with the individual with the mental disability.

Instrumentation

To gather responses, the researcher developed a 17 question, 115 item written questionnaire entailed, “Survey of Caregivers’ Decisions Regarding Placement,” to identify and analyze variables influencing family members’ decisions regarding continued placement of family members with mental disabilities in a state-operated mental retardation institution. The survey questionnaire used in this study was developed using several similar questionnaires found in the literature as a guide. Of the 17 questions, two questions (7 & 10) were taken from the Survey of Families with a Developmentally Disabled Family Member by Tausig (1985); and two questions (11 & 12) were taken from the Survey of Parents of Children with Developmental Disabilities by Sherman (1988). The remaining questions were generated and modified from the National Survey of the Families of Institutionalized Mentally Retarded Persons by Spreat, Telles, Conroy, Feinstein, and Colombatto (1987). All three questionnaires used were designed to assess families' perceptions of residential services. Reliability and validity information was sought from the authors of each of the survey questionnaires used. Although attempts were made, the authors for each questionnaire did not provide any reliability or validity data for their respective instruments.

The 17 question survey questionnaire used was divided into three parts. Part I consisted of questions 1 through 14 that sought information about the respondents' personal characteristics. This information focused primarily on demographic information. Specifically, the characteristics investigated gender, age, marital status, number of children, ethnic group membership, level of income, grade level completed and level and type of disability of the respondents' family member. Respondents were asked to check or circle the appropriate answers in the space provided.

Part II of the questionnaire was that focused on choices considered important to seek and maintain placement of a family member in a state-operated institution. Part II was a two-part, 19-item each placement survey using a five-point Likert-type scale designed to determine level of importance that selected variables had on respondents' choice to seek initial placement and to maintain placement. Likert scale values and levels of importance were (1) not important, (2) slightly important, (3) somewhat important, (4) important, and (5) very important.

Part III of the questionnaire focused on facility satisfaction. This section includes 15 items. The facility survey using a five-point Likert-type scale designed to determine level of satisfaction provided at the facility. Likert scale values and levels of satisfaction were (1) not very dissatisfied, (2) somewhat dissatisfied, (3) neutral, (4) somewhat satisfied, and (5) very satisfied.

Family members were asked to complete a battery of questions that assessed family involvement and variables such as demographic information. The instrument measuring these variables required respondents (family members) to answer questions about themselves and selected individual(s) to whom he/she was related or for whom he/she advocated.

Pilot Test of the Instrument

The questionnaire items were screened and reviewed by members of the researcher's doctoral committee for content and clarity. The survey questionnaire was pilot tested on February 17, 2006, using three family members of residents at Southwood State School. Respondents were asked to complete all sections of the questionnaire and to note questions that they had concerning readability, intent of question, concerns about questions' content and format and recommended suggestions for changes. The length of time required to complete the pilot questionnaire (approximately 15 minutes) was documented. After the pilot testing, the results were analyzed, and the researcher made minor revisions to the questionnaire based on the recommendations received. The final instrument was printed and distributed to family members on March 21, 2006. The instrument was printed double-sided using a 10-point font on canary colored 8.5” x 11” paper.

Collection of Data

After approval from the Institutional Review Board (IRB), a letter was provided to the Superintendent of Southwood State School to seek permission to conduct the study at his campus and to access information of residents residing at this facility (See Appendix A.) Participants were selected using purposive sampling from Southwood State School’s Daily Census Data.

Steps in Research

Step 1. Gather Information

The researcher performed record reviews and visited with the Residential Directors in five departments at Southwood (Lavaca, Three Rivers, Leon, Trinity, & Neches) and their Qualified Mental Retardation Professionals (QMRP).

Step 2. Identify the Participants

Through record reviews and interviews, the researcher was able to obtain needed information that helped identify the participants in the study. Criteria used to identify residents family members for participation included having first to identify their family member with mental disabilities residing at Southwood State School. The researcher sought to identify residents with the capability to perform some activities of daily living. Activities of daily living (ADL's) refers to basic tasks of everyday living to include such things as eating, bathing, dressing, toilet training, working, and so forth. Through record reviews and interviews, 86 residents met the sample criteria however; five residents were excluded because of correspondent information to whom to send the survey questionnaire. The remaining 81 family members' were identified using the Southwood State School family contact database to which the questionnaire would be mailed.

Step 3. Mailing Questionnaire

The packets to be mailed were taken to the Management and Program Evaluation Services Department at Southwood State School where they were assembled, and envelopes were addressed to prospective respondents. Southwood State School did not release personal information (addresses, telephone numbers, identifying information, etc.) to the researcher, but mailed the packets for the researcher.

First Mailing. On March 21, 2006, 81 family members were mailed a cover letter, which accompanied the survey questionnaire and a postage-paid return envelope, using first-class postage rate to their homes. Respondents were asked to complete a battery of questions that assessed family involvement and caregiver variables. At the request of the Superintendent of Southwood State School, a cover letter signed by him explained the purpose of the study and how the data would be used to benefit the student (Appendix B). The prospective respondents were asked to return the completed survey in the self-addressed, postage-paid envelope provided. Each instrument was coded with a three-digit number to track, which individuals responded and to assist in follow-up with non-respondents. Respondents were informed that all participation was voluntary and responses would be confidential. Prospective respondents were informed that neither their names nor any information identifying the respondent would be associated with the information provided in the completed survey.

Second Mailing/Follow-ups. On April 13, 2006, a follow-up post card was sent using first-class postage rate to the targeted family members who had not responded to the initial request for information. The post card measured 4” x 6” and was printed on ivory-colored paper (Appendix C). The card served as a reminder to those who had not responded to the survey and requested that they complete and return the survey by April 28, 2006.

Because of the low rate of return of completed surveys, the researcher sought assistance from social workers within the five departments at Southwood (Lavaca, Three Rivers, Leon, Trinity, and Neches) to facilitate communication with family members who had not replied to the initial mail outs. Follow up telephone calls were made by the social workers to those individuals who had been mailed survey questionnaires. This communication assisted the researcher in getting follow-up survey questionnaires to family members who either had not received it, lost it and needed a replacement, or had not responded previously. Most family members contacted through these follow-up procedures responded by returning the completed questionnaire. The study began with 86 identified participants. Of the 86, five were excluded because the facility’s database did not have any correspondent information to whom to send the survey questionnaire. The remaining 81 were mailed questionnaires. One of the 81 mailed surveys was returned due to an incorrect address. Fifty-one completed questionnaires were returned out of the 80 yielding a return rate 63.75%.

Analysis of Data

Data were obtained from the 17 question questionnaire, entitled, “Survey of Caregivers’ Decisions Regarding Placement.” For the study, data analysis was conducted using the follow procedure, 1) entry of data and 2) analysis of data.

Step One - Entry of Data

The researcher assigned a three-digit code number ranging from 001 to 081 to each questionnaire. Each item or variable on the questionnaire was given a corresponding code that facilitated analysis of the data and comparison of the requested information. Respondent information initially was input into Microsoft Excel and checked for accuracy, and statistical comparisons were conducted using the Statistical Package for Social Sciences (SPSS) (SPSS, Inc. 2003). From the questionnaires, 115 variables were entered for analysis.

Step Two - Analysis of Data

Quantitative data were analyzed using correlational statistics from the survey questionnaire responses of family members. The Statistical Package for Social Sciences (SPSS) was used to perform statistical analysis of the data. Data generated from the instruments were both descriptive and comparative. Descriptive statistics were used for reporting personal characteristics of the family members. The SPSS procedure FREQUENCIES was used to calculate frequencies and percentages for all of the variables. The SPSS procedure CROSSTABS was used to produce Spearman and

Pearson correlations to measure the relationships between variables that were interval and those that were ordinal. Conclusions of the study were reported using tables, numerical and graphical techniques. Data collected from responses of family members were further reported in narrative form. The findings yielded from these procedures are presented and discussed in Chapter IV.

CHAPTER IV

FINDINGS AND DISCUSSION

The purpose of the study was to identify the variables influencing family members' decisions regarding continued placement of family members with mental disabilities in state-operated mental retardation institutions.

The following research questions were identified to accomplish the purpose of the study:

1. What variables do family members use to seek initial placement of family members with mental disabilities in state-operated mental retardation institutions?
2. What variables do family members use to maintain placement of family members with mental disabilities in state-operated mental retardation institutions?
3. How do family members assess the quality of services provided in a state-operated institution?
4. To what extent do personal support variables (emotional, financial, social, physical/health and facility) impact family members' decision to maintain institutional placement?

The questions served as a guide for presenting the findings of the study. Information concerning each question will be presented in separate sections.

Demographic Information

The researcher first sought to identify the personal characteristics (e.g., age, gender, marital status, ethnicity, income, etc.) of respondents. The information is presented in the tables that follow.

The age of respondents ranged from 26 years old to 95 years old. The mean age of respondents was 61.17 years old as illustrated in Table 4.1. Within the study, age of respondents aligned fairly evenly above or below the 50 percentile range. Four subjects did not provide information on age.

Table 4.2 presented frequencies and percents of the respondents' gender. Males (n=12) comprised 23.5% of the respondents, and females (n=39) comprised 76.5% of the respondents.

Information on the relationship to the person with the mental disability is presented in Table 4.3, Mothers (n=21) comprised 41.2% of the respondents. Sisters (n=14) comprised 27.5% of the respondents. Fathers (n=5) comprised 9.8% of the respondents, followed by Brothers (n=4) comprising 7.8% of respondents, and Mothers and Fathers responding together (n=3) comprising 5.9% of the respondents.

Table 4.4 indicates that the majority (56%) of the respondents were married at the time their relative was initially placed in a state-operated mental retardation institution. Twenty percent reported that they were single at the time of initial placement, 14% reported that they were divorced, and 4% reported that they were either separated or widowed. One subject did not provide information on marital status at the time of initial placement.

As described in Table 4.5, the greatest majority of respondents (n=27) reported that they currently were married (54%). Nine respondents (18%) indicated that they never were married. Eight respondents (16%) indicated that they currently were widowed. Divorcees (n=5) comprised of 10% of the respondents. One respondent (2%) reported being currently separated. One subject did not provide information on current marital status.

Table 4.6 describes the ethnicity of respondents. European Americans (White) (n=32) comprised 62.7% of the respondents. Hispanics (n=7) comprised 13.7% of the respondents. Both African American (n=5) and Native American (n=5) comprised 9.8% of the respondents. Two individuals (3.9%) reported that they were of other ethnic origin.

Table 4.7 provides information on respondents' educational attainment. Eleven respondents (26.2%) reported having some college education. The remaining 31 responded as follows: Six respondents (14.3%) reported that they either had some high school or had completed high school, and five respondents (11.9%) reported having a junior college or business degree, a college degree, or a graduate degree. Four respondents (9.5%) reported having a grade school education. Nine subjects did not provide information on education.

Table 4.1 Age of Respondents

Age	N	%
26	1	2.1
31	1	2.1
33	1	2.1
36	1	2.1
38	1	2.1
40	2	4.3
42	3	6.4
46	1	2.1
48	1	2.1
50	1	2.1
54	2	4.3
55	1	2.1
57	1	2.1
58	1	2.1
59	1	2.1
61	2	4.3
62	2	4.3
64	2	4.3
65	1	2.1
66	3	6.4
67	1	2.1
70	1	2.1
71	1	2.1
72	1	2.1
73	2	4.3
74	2	4.3
75	1	2.1
76	1	2.1
78	2	4.3
79	1	2.1
82	1	2.1
83	2	4.3
84	1	2.1
95	1	2.1
Total	51	100

[a] Four subjects did not provide a response.

Table 4.2 Gender of Respondents

Gender	N	%
Male	12	23.5
Female	39	76.5
Total	51	100

Table 4.3 Relationship to the Person with the Disability

Relationship to the person with the disability	N	%
Mother	21	41.2
Mother & Father	3	5.9
Sister	14	27.5
Father	5	9.8
Brother	4	7.8
Other	4	7.8
Total	51	100

Table 4.4 Marital Status at Time of Initial Placement

Marital status at time of initial placement	N	%
Married	28	56.0
Divorced	7	14.0
Separated	1	2.0
Widowed	2	4.0
Never Married	10	20.0
Other	2	4.0
Total	50	100

[a] One subject did not provide this information.

Table 4.5 Current Martial Status of Respondents

Current Marital Status	N	%
Married	27	54.0
Divorced	5	10.0
Separated	1	2.0
Widowed	8	16.0
Never Married	9	18.0
Other		
Total	50	100

[a] One subject did not provide this information.

Table 4.6 Ethnicity of Respondents

Ethnicity	N	%
European American	32	62.7
African American	5	9.8
Hispanic American	7	13.7
Native American	5	9.8
Other	2	3.9
Total	51	100

Table 4.7 Education of Respondents

Education	N	%
1.Grade School	4	9.5
2. Some High School	6	14.3
3.Completed High School	6	14.3
4.Some College	11	26.2
5. Junior or Business Degree	5	11.9
6. College Degree	5	11.9
7. Graduate School	5	11.9
Total	42	100

[a] Nine subjects did not report this information.

Table 4.8 Education of Respondents' Spouses

Education of spouse	N	%
1. Some High School	7	26.9
2. Completed High School	5	19.2
3. Some College	4	15.4
4. Junior or Business Degree	1	3.8
5. College Degree	6	23.1
6. Graduate School	3	11.5
Total	26	100

[a] Data reflect only those reported to have spouses.

Data on educational attainment of respondents' spouses is reflected in Table 4.8. Seven respondents (26.9%) reported that their spouses had at least some high school education. Six respondents (23.1%) reported that their spouse had a college degree. Five (19.2%) reported their spouses as having completed high school and four (15.4%) reported their spouses as having some college but no college degree. Three respondents (11.5%) indicated that their spouses held a graduate degree and one respondent (3.8%) reported their spouse as having a junior college or business degree. Twenty-four subjects did not provide information on their spouse's education.

Table 4.9 shows that of the 51 respondents, 12 (32.4%) reported an annual income between $10,000 and $25,000. The remaining 25 responded as follow: five respondents (13.5%) reported their annual income to be in the under $10,000 range and five reported their income in the range of $25,000 to $40,000, (13.5%) respective. Four respondents (10.8%) indicated that their annual income was $40,000 and $55,000. Three subjects (8.1%) in three separate categories indicated that their annual incomes were between the ranges of $70,000 and $85,000, $85,000 and $100,000, and the over $100,000 categories. Two respondents (5.6%) in two separate categories reported that they had annual incomes between the $55,000 and $70,000. Fourteen subjects did not provide information on annual income.

Table 4.10 indicates whether respondents received additional forms of financial assistance to supplement their primary source of income. Twenty-three respondents (45.1%) indicated that they currently received social security as supplemental income to

Table 4.9 Income of Respondents

Income	N	%
under 10,000	5	13.5
$10,000 -25,000	12	32.4
$25,000-40,000	5	13.5
$40,000-55,000	4	10.8
$55,000-70,000	2	5.4
$70,000-85,000	3	8.1
$85,000-100,000	3	8.1
over $100,000	3	8.1
Total	37	100

[a] Fourteen subjects did not report income information.

Table 4.10 Forms of Financial Assistance

Financial Assistance	N	%
AFDC	---	---
SSI	5	9.8
Medicare	19	37.3
Pension	6	11.8
Family/Friends	---	---
Unemploy. Ins.	---	---
TRS	5	9.8
Soc. Security	23	45.1
Disability	2	3.9
Housing Asst.	---	---
None	16	31.4
Other	1	2.0
Total	77	151.1

[a] Some subjects identified multiple forms of assistance.

[b] The total percent is greater than 100 due to multiple replies.

their primary source of income. Nineteen subjects (37.3%) reported receiving Medicare or Medicaid, while sixteen respondents (31.4%) reported that they did not receive any form of additional financial assistance. Six subjects (11.8%) reported receiving some form of pension and five respondents (9.8%) reported receiving either teacher retirement benefits or Supplemental Security Income (SSI). Two respondents (3.9%) reported receiving some form of disability benefits as a form of financial assistance.

Table 4.11 describes the identified developmental disabilities of respondents' family members. The majority of respondents (92.2%) reported that their family member had a primary diagnosis of mental retardation. Eleven respondents (23.5%) reported that their family member had a seizure disorder, while eight respondents (15.7%) indicated that their family member had cerebral palsy. Seven respondents (13.7%) indicated that their family member was present with neurological disorders or other forms of developmental disabilities.

Level of mental retardation is reflected in Table 4.12. These data reflect that most respondents (n=20) reported that their family member functioned in the severe range of mental retardation (41.7%). The remaining 28 responded as follows: thirteen respondents (27.1%) reported that their family member functioned in the profound range of mental retardation. Eight respondents (16.7%) reported that their family member functioned in the moderate range of mental retardation. Four respondents (8.3%) reported their family member's level of mental retardation as mild mental retardation. Two respondents (4.2%) reported their family member's level of mental retardation as not known. Three subjects did not provide information on level of mental retardation.

Table 4.11 Identified Developmental Disabilities

Disability	N	%
Autism	3	5.9
Cerebral Palsy	8	15.7
Seizure	12	23.5
Mental Retardation	47	92.2
Neuro. Impairment	7	13.7
Mental Health Dis.	7	13.7
Total	84	164.7

[a] Some subjects identified multiple disabilities.

[b] The total percent is greater than 100 due to multiple replies.

Table 4.12 Level of Mental Retardation

Level of MR	N	%
Not retarded	1	2.1
Mild MR	4	8.3
Moderate MR	8	16.7
Severe MR	20	41.7
Profound MR	13	27.1
Not known	2	4.0
Total	48	100

[a] Three subjects did not report this information.

Findings Related to Question 1

Research Question 1 – What variables do family members use to seek placement of family members with mental disabilities in state-operated mental retardation institutions? The analysis of data is reported in Tables 4.13 and 4.14. Data revealed that 74.5% of respondents indicated that the circumstances or events, which caused them to seek initial placement, were because their family member with the disability could receive more intensive care and/or specialized programs in the state-operated institution. Also, 64.7% of respondents reported their family member with the disability could not live independently as the reason they sought initial placement. Additionally, 56.9% of respondents reported that they could not get the needed services in the home to care properly for their family member with the disability. Moreover, 51% of respondents reported behavioral problems as the event or circumstance that caused them to seek initial placement of their family member into a state-operated institution. Respondents (39.2%) reported advice of physicians or other medical specialists as a circumstance that caused them to seek placement in a residential facility.

Table 4.14 illustrated choices many respondents' considered in their decisions to seek placement of their family members with a mental disability in a state-operated institution. The data indicated how many respondents selected each level of importance. The Likert-type scale used in the mailed questionnaire ranged from one to five, one being not important and five being that the decision was very important on the respondents' choice.

Table 4.14 indicates that, of the 19 variables listed, the need for a more protected place/secure environment (M = 4.50) was very important when deciding to seek placement of their family member. Pressure from relatives and friends (M = 1.34) was least important to respondents, as a group, in seeking institutional placement of a family member with a disability. On the Likert-type scale, respondents, as a group, ranked that the need for 24-hour supervision (M = 4.48), difficulty of physical care (M = 4.10) and trouble managing their family members' behaviors (M = 4.06) as being very important in their decision to seek placement. Trouble getting help to care for their family member (M =4.05) also was very important to respondents' decisions to seek placement.

Regarding to advice of doctors and other professionals and supportive services in the community, respondents reported that they were important to very important in their decisions to seek placement. Money problems were reported by respondents to be somewhat important to important. At the same time, respondents, as a group, reported problems in the marriage (M = 1.68) as not important to slightly important in their decisions to seek initial placement based on the fact that this particular variable was ranked low in terms of level of importance.

Table 4.13 Circumstances Influencing Respondents’ Decisions to Seek Initial Placement

Variables	%
Could not live Independently	64.7
Behavior Problems	51.0
Could receive more care & special programs	74.5
Advice of physician or medical specialist	39.2
Financial Problems	39.2
Legal Problems	2.0
Death or illness of caretaker in family	11.8
Health Problems	21.6
Disruption of family life	35.3
Couldn’t get needed services in home	56.9
Other	7.8
Total	404

[a] Some subject identified multiple circumstances.
[b] The total percent is greater than 100 due to multiple replies.

Table 4.14 Variables Influencing Respondents’ Decisions to Seek Placement

Variables	Mean Score	Std. Dev.
Difficulty of physical care	4.10	1.309
Advice of doctor or other professional	3.81	1.418
Money problems	2.67	1.426
Illness in family	2.53	1.533
Problems in marriage	1.68	1.312
Difficult for other children in family	2.52	1.592
Hurt relationship with relatives and friends	1.68	1.105
Pressure from relatives and friends	1.34	.693
Relatives need for medical care	2.89	1.674
Need for non-medical services	3.95	1.430
Need for more protected environment	4.50	.851
Trouble getting help to care for him/her	4.05	1.379
Trouble managing behavior	4.06	1.405
Your health status	2.88	1.451
Your age	2.95	1.564
Your relatives age	2.95	1.673
24-hr/ supervision	4.48	1.031
Supportive services in community	3.39	1.611
Other	3.14	2.035

Findings Related to Question 2

Research Question 2 – What variables do family members use to maintain placement of family members with mental disabilities in state-operated mental retardation institutions? The analysis of data is reported in Tables 4.15 and 4.16. Data in Table 4.15 indicated that 82.4% of respondents choose to maintain placement of their family members because they could receive more intensive care or specialized programs at the facility. Also, 78.4% reported that their family member with a disability's lack of independent living skills was a reason to maintain placement. In addition, 66.7% indicated that they choose to maintain placement because of the security of the institution, followed by their family members need for medical services (56.9%). Still further, 54.9% of respondents reported that they maintain placement of their family member because they feel that they cannot get needed services in the home to care for them there. Respondents (51%) also reported their family members' level of disability as a reason why they choose to maintain placement. Moreover, 47.1% of respondents reported that they choose to maintain placement because of the behavioral services provided in the institution. Respondents (43.1%) reported the need for more freedom of movement as a choice in maintaining placement for their family member. Health problems (41.2%) were indicated by respondents as a reason why they chose to maintain placement.

Table 4.16 illustrates the importance of respondents' decisions to maintain placement of their family members with a mental disability in a state-operated institution. The data indicate how many respondents selected each level of importance. The Likert-type scale used in the mailed questionnaire ranged from one to five, one being not important and five being very important on the respondents' choice.

Table 4.16 reports that, of the 19 variables listed, the need for 24-hour supervision (M = 4.81) was important to very important to respondents, as a group, in their decision to maintain placement of their family member. Pressure from relatives and friends (M = 1.53) was least important to respondents, as a group, in maintaining institutional placement of a family member with a disability. Respondents, as a group, further indicated the need for a more protected/secure environment (M = 4.77), trouble getting help to care for their family member with the mental disability (M = 4.56) and the need for non-medical service (M = 4.43) such as work, school, speech, toilet training, etc. was important to very important variables in their decision to maintain their family members' current placement. Respondents also reported that because of difficulty with their family members physical care (M = 4.30), along with trouble managing their behaviors (M = 4.28) it was important to very important that they maintain placement in a state-operated institution. Again, advice of doctors and other professionals and supportive services in the community were reported by respondents, as a group, as somewhat important to important in their decisions to maintain their current placement.

In terms of importance in their decisions to maintain placement, respondents indicated the following: health status (M = 3.68), their age (M = 3.69), their relatives' age (M = 3.45), and their relatives' need for medical care (M = 3.34), were somewhat important to important in their decisions to maintain placement.

Incidentally, respondents, as a group, ranked the need for a more protected environment, 24-hour supervision, and the fact that they could not get needed services in the home as very important in their decisions to both seek and maintain placement in a long-term residential facility.

Table 4.15 Circumstances Influencing Respondents' Decisions to Maintain Placement

Variables	%
1. Lack independent living skills	78.4
2. Behavior Services	47.1
3. Could receive more care & special programs	82.4
4. Advice of physician or medical specialist	37.3
5. Medical Services	56.9
6. More Freedom of movement	43.1
7. Level of disability	51.0
8. Death or illness of caretaker in family	13.7
9. Security of institution	66.7
10. Other	5.9
11. Health Problems	41.2
12. Disruption of family life	29.4
13. Couldn't get needed services in home	54.9
14. Age of caregiver	35.3
15. Other	3.9
Total	647.2

[a] Some subject identified multiple circumstances.

[b] The total percent is greater than 100 due to multiple replies.

Table 4.16 Variables Influencing Respondents' Decisions to Maintain Placement

Variables	Mean Score	Std. Dev.
Difficulty of physical care	4.30	1.140
Advice of doctor or other professional	3.79	1.389
Money problems	3.02	1.666
Illness in family	2.63	1.593
Problems in marriage	1.68	1.289
Difficult for other children in family	2.24	1.685
Hurt relationship with relatives and friends	1.75	1.235
Pressure from relatives and friends	1.53	.960
Relatives need for medical care	3.34	1.726
Need for non-medical services	4.43	1.129
Need for more protected environment	4.77	.698
Trouble getting help to care for him/her	4.56	.808
Trouble managing behavior	4.28	1.277
Your health status	3.68	1.439
Your age	3.69	1.522
Your relatives age	3.45	1.663
24-hr/ supervision	4.81	.398
Supportive services in community	3.98	1.475
Other	3.00	2.191

Findings Related to Question 3

Research Question 3 - How do family members assess the quality of services provided in state-operated institutions? The analysis of data is reported in Table 4.17.

Table 4.17 reports the respondents' assessment of the quality of services provided in state-operated mental retardation institutions. The data indicate how many respondents selected each level of satisfaction. The Likert-type scale used in the mailed questionnaire ranged from one to five, one being very dissatisfied with services and five being very satisfied with services provided by the facility.

Overall, respondents' indicated that they were very satisfied with services provided at the residential facility. Specifically, respondents, as a group, reported that they were very satisfied with recreation (M = 4.80) provided at the residential facility. Recreation includes, but is not limited to trips, sports, arts and crafts, etc. Respondents, as a group, indicated they were least satisfied with learning opportunities or improving basic reading, writing, and use of numbers. However, on this variable, respondents' views were neutral to somewhat satisfied with this service provided by the facility.

Respondents ranked a secure and permanent home and professional service as the second and third most satisfying things about the residential facility. Respondents, as a group, reported that they were somewhat satisfied to very satisfied that their family member had a secure and permanent home (M = 4.75) and could receive professional services (M = 4.75) at the institution.

Additionally, on the Likert-type scale used in the study, respondents, as a group, ranked protection from harm (M = 4.57), freedom of movement (M = 4.54), and active treatment (M = 4.48) as services with which they were somewhat satisfied to very satisfied with provided by the facility.

Table 4.17 Variables on Services Provided by the Facility

Variables	Mean Score	Std. Dev.
Recreation	4.80	.499
Learning/self-care	4.25	1.101
Keeping active and busy	4.45	.937
Medical Services	4.43	.913
Secure/permanent home	4.75	.636
Learning and improving social skills	4.46	.982
Getting rid of problem behaviors	4.26	.966
Physical comfort	4.47	.819
Learning and improving basic reading, writing, and numbers	3.83	1. 039
Protections from harm	4.57	.866
Preparation and training for work	4.19	.876
Quality staffing	4.42	.986
Active treatment	4.48	.772
Professional Services	4.75	.565
Freedom of movement	4.54	.771

Findings Related to Question 4

To respond to question four, it was important that each variable be reviewed individually.

Research Question 4 -To what extent do personal support variables (emotional, financial, social, physical/health and facility) impact family members' decision to maintain institutional placement?

Five personal support variables were also examined to identify the degree to which emotional supports, financial supports, physical/health supports, social supports and facility supports impacted family members' decisions to maintain institutional placement of a family member with a mental disability. In an effort to address these questions, the researcher used five scales comprised from items on the five-point Likert-type scale used in the mailed questionnaire. The emotional supports scale included for items, the financial support scale included one item, the social support scale included three items, the physical/health supports scale included six items, and the facility supports scale included 18 items. Internal consistency reliabilities (Cronbach's alpha) were computed separately for all relevant measurement scales. Three scales reported adequate levels of internal consistency with Cronbach's alphas of .863 (facility supports), .703 (physical/health supports), and .656 (emotional supports) respectively. The Likert-type scale was used for analysis because according to Gall, Gall, and Borg (2003) items used for measuring the internal consistency of scales should not be dichotomous in nature (i.e. yes/no type responses).

Table 4.18 further provides data on scales regarding the degree to which each personal support: emotional supports, financial supports, physical/health supports, social supports, and facility supports, impact family members' decisions to maintain placement in state-operated institutions. Respondents, as a group, ranked facility supports as a factor in their decisions to maintain placement. Facility supports include such things as, the need for non-medical services, the need for a more protected place/secure environment, the need for 24-hour supervision, along with all 15 items involving facility services from the mailed questionnaire. Respondents, as a group, reported that facility supports were important to very important (M=4.42) in their decisions to maintain placement. Further, as a group, respondents reported that they were somewhat satisfied to very satisfied with facility supports. Additionally, respondents, as a group, ranked social supports as being important to very important (M=4.13) in their decisions to maintain institutional placement of their family member with a mental disability. Social supports include the following items from the five-point Likert-type scale: advice of doctors or other professionals, trouble getting help to care for him/her, and lack of supportive services in the community. Data on the scale of physical/health supports reported that the decisions to maintain placement were somewhat important to important to respondents (M=3.74). Physical/health supports include items such as the difficulty of physical care, illness in the family, trouble managing his/her behaviors, the health status of the caregiver, the age of the caregiver, and the age of the person with the developmental disability.

The supports that had the least impact on family members' decisions to maintain placement included the emotional and financial supports. The scale items include such items as problems in the family members' marriage, difficulty for other children in the family, hurt relationships with other relatives and friends and pressure from relatives and friends. On these scales respondents, as a group, reported they were not important to slightly important (M=1.84) in their decisions to maintain placement of their family member with a mental disability. Since the financial supports scale had only one item, money problems, the question was not measured for internal consistency. Data however, reported that respondents, as a group, felt that money problems were not important in their decisions to maintain placement.

Findings suggest that among the personal support variables, a facility, social and physical/health support does play a role in family members' decisions to maintain placement in a state-operated institution. Also, although there was internal consistency measured for the scale items of emotional supports as evidenced by a Cronbach's alpha of .656, data revealed that the respondents, as a group, felt this scale was not important in their decision to maintain placement.

Table 4.18 Personal Support Variables

Scales	Mean Score	Std. Dev.
Physical/Health Supports Scale	3.74	.942
Emotional Supports Scale	1.84	1.018
Social Supports Scale	4.13	.762
Facility Supports Scale	4.42	.578

CHAPTER V

SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS

Summary

The purpose of the study was to identify the variables’ influencing family members’ decisions regarding continued placement of family members with mental disabilities in state-operated mental retardation institutions.

The following research questions were identified to accomplish the purpose of the study:

1. What variables do family members use to seek initial placement of family members with mental disabilities in state-operated mental retardation institutions?
2. What variables do family members use to maintain placement of family members with mental disabilities in state-operated mental retardation institutions?
3. How do family members assess the quality of services provided in a state-operated institution?
4. To what extent do personal support variables (emotional, financial, social, physical/health and facility) impact family members’ decision to maintain institutional placement?

The population for the study was family members’ of adults with mental retardation receiving services in one state-operated mental retardation institution (n=51), as identified by the Southwood State School Daily Census Report. The researcher conducted the study using family members selected as having a family member with a disability who had the capability to move into a community-based setting.

The ethnic breakdown of the respondents was determined to be European Americans (n=32), which comprised 62.7% of the respondents, Hispanics (n=7) comprised 13.7% of the respondents, and African American (n=5) and Native American (n=5) comprising 9.8% of the respondents. Two individuals (3.9%) reported their ethnic origin as other.

The instrument used in this study was developed using several similar questionnaires found in the literature as a guide. The 17 question survey questionnaire entailed, “Survey of Caregivers’ Decisions Regarding Placement,” was used. Within the 17 question survey questionnaire, two questions (7 & 10) were taken from the Survey of Families with a Developmentally Disabled Family Member by Tausig (1985); and two questions (11 & 12) were taken from the Survey of Parents of Children with Developmental Disabilities by Sherman (1988). The remaining questions were generated and modified from the National Survey of the Families of Institutionalized Mentally Retarded Persons by Spreat, Telles, Conroy, Feinstein, and Colombatto (1987). The questionnaire used was divided into three parts: Part I consisted of questions one through 14 and sought information about the respondents’ personal characteristics. This information focused primarily on demographic information. Specifically, the characteristics investigated gender, age, marital status, number of children, ethnic group membership, level of income, grade level completed and level and type of disability of the respondents’ family member. Respondents were asked to check or circle the appropriate answers in the space provided.

Part II was a two-part 19-item placement survey using a five-point Likert-type scale designed to determine level of importance that selected variables had on respondents’ choice to seek initial placement and to maintain placement. Likert scale values and levels of importance were (1) not important, (2) slight important, (3) somewhat important, (4) important, and (5) very important.

Part III was a 15-item facility survey using a five-point Likert-type scale designed to determine level of satisfaction provided at the facility. Likert scale values and levels of satisfaction were (1) not very dissatisfied, (2) somewhat dissatisfied, (3) neutral, (4) somewhat satisfied, and (5) very satisfied.

On March 21, 2006, a cover letter, the instrument, and a postage-paid return envelope were mailed using first class postage rate to identified family members. On April 13, 2006, a follow-up post card was sent using first-class postage rate to the targeted family members who had not responded to the initial request for information. The post card served as a reminder to those who had not responded to the survey and requested that they complete and return the survey by April 28, 2006. Because of the low rate of return of completed surveys, the researcher sought assistance from social workers at Southwood State School to facilitate communication with family members who had not replied to the initial mail outs.

Of the 81 mailed questionnaires, one questionnaire was returned to Southwood State School as undeliverable due to an incorrect mailing address. Fifty-one completed questionnaires were returned out of the 80. This yielded a return rate of 63.75%. The data collection phase was concluded on July 14, 2006.

The SPSS procedure FREQUENCIES (SPSS, Inc., 2003) was employed to calculate frequencies and percentages for all of the variables of the family members. To determine relationships between and among variables, the SPSS procedure CROSSTABULATION (SPSS, Inc. 2003) was used to produce SPEARMAN CORRELATIONS to quantify relationships between nominal and ordinal variables.

Conclusions

The conclusions of this study are based on the findings from data collected and analyzed in this investigation. Each conclusion is followed by the findings from the research that supports or refutes them.

What variables do family members' use to seek placement of family members with mental retardation in state-operated institutions?

1. When family members sought initial placement the fact that their family member with the mental disability could receive more intensive care and/or specialized programs in the state-operated institution was important to them. This was supported by the fact that their family member lacked independent living skill and exhibited problem behaviors that were becoming more difficult for them to manage. Additionally, family members reported that they could not get the needed services in the home to properly care for their family member with the disability. This lends credence to the studies by Hill (1958) and McCubbin (1979), who suggested that the availability of social supports community service systems and difficulty in managing the individual's maladaptive

behaviors exerted an important influence on family members' decisions. Another interesting finding was that advice of physicians and/or other medical and professional specialists were instrumental in the decision making of many family members. This bolsters the literatures claims which suggest that early advice to parents by professionals and physicians was instrumental in parent's decisions to institutionalize their children with mental disabilities (Gorham, 1975). Moreover, family members seeking placement, do so because of high levels of or difficulty in managing maladaptive behavior (Black et al., 1985; Hobbs, 1964; Shellhaass & Nihira, 1969; Sherman, 1988).

2. Additionally, respondents were more likely to seek institutional placement because they felt that their family member was in need for a more protected place/secure environment and 24 hour supervision. Most family members reported that they experienced difficulty with their family member's physical care. Trouble getting help to care for their family member with a mental disability was also very important to respondents' decision to seek placement. This finding supports the literature that suggested that caregiver's request initial placement because of problems with general care and supervision (Black, Cohn, Smull & Crites, 1985; Black, Molaison, & Smull, 1990; Wolf & Whitehead, 1975).

3. It is interesting to note however, that problems in the marriage and pressure from relatives and friends were reported to have the least influence on family members' placement decisions. This finding thus refutes conclusions in the literature which suggested that, interference with family life (Hill, 1958; McCubbin, 1979), pressure from relatives and friends, and the presence of other family problems played a role in the

decision to seek initial placement (Fotheringham, Skelton, & Hoddinott, 1972; Graliker & Koch, 1965; Wolf & Whitehead, 1975).

What variables do family members' use to maintain placement of family members with mental retardation in state-operated institutions?

1. Receiving more intensive care or specialized programs at the facility was also important to family members. Most felt that do to a lack of independent living skills, and their family member's level of disability there was a great need for a more protected/secure environment of the institution. Many family members' reported that their relative with the disability was also in need of medical services which they felt the facility could more adequately provide. Additionally, 54.9% of respondents reported that their own health problems and the fact that they cannot get needed services in the home to care for their family member was important in their decisions to maintain placement. Moreover respondents reported the family members with the disabilities could receive more freedom of movement in the institutions.

2. Respondents were more likely to maintain placement for reasons similar to those identified when seeking placement. For family members' the need for 24-hour supervision because of difficulty with their relatives' physical care along and troubled behaviors was reported to exert influence on placement decisions. As was their family members need for non-medical service such as work, school, speech, toileting training, etc. Again, advice of doctors and other professionals and supportive services in the community were reported by respondents, as having a very important influence in their decisions to maintain their current placement.

Incidentally, findings from this study on decisions to seek were somewhat identical to the findings concerning their decisions maintain placement. In both instances, respondents reported that placement considerations were influenced by availability of 24 hour supervision, caregiver social and community support systems, problems in dealing with the general care and supervision of the person with the mental disability, the severity of the disability, greater medical or physical care needs and high levels of maladaptive behaviors.

3. Family members' reported their health status and age, as well as their relative with the disabilities age and need for medical care, did play a critical role in their decisions to maintain placement. This finding supports studies by Fotheringham, Skelton, & Hoddinott (1972); Graliker & Koch, (1965); and Wolf & Whitehead, (1975), that parent's age and health status were identified as playing a role in their decisions regarding placement.

4. The identified disability most often reported by respondents was mental retardation (92.2%), with a majority of respondents reporting that their family member fell within the severe (41.7%) to profound levels (27.1%). Also, respondents stated that their family member with the disability presented many times with a seizure disorder. This information supports the findings in the studies by Allen (1972); Downey (1965); and Saenger (1960) that the degree of disability and level of functioning of the family member with the developmental disability was highly related to the decision to place.

How do family members' assess the quality of services provided in a state-operated institution?

1. In this study family members' appeared to have a preference for institutional services for their family member with the disability. These family members' overwhelmingly reported that they were very satisfied with services provided at the residential facility. Specifically, respondents were more satisfied with recreation, which included trips, sports, arts and crafts, etc. and the availability of professional service provided at the facility such as psychological, social work, and QMRP services. Maintaining a secure and permanent home was also crucial to family members'. They as a group, ranked it as an important service provided by the facility. Additionally, respondents, as a group, ranked protection from harm, freedom of movement, and active treatment as services they were very satisfied with that were provided by the facility. These finding are consistently supports finding in the literature that family members continue to strongly support and had a distinct preference for the institution services. For instance, in studies conducted by Brockmeier (1975); Willer, Intagliata, and Atkinson (1979); Meyer (1980); Conroy (1984); and Payne (1976), the authors reported consistently high levels of satisfaction with services provided in institutions among families of people with mental disabilities. Frohboese and Sales (1980) and Payne (1976) in their studies further reported that institutions offered greater freedom of movement, independence, safety, a permanent home and advantages of a concentration of mental retardation experts.

Although this study was predicated on the general theory of normalization which suggests that, the environment in which an individual with a mental disability lives has an impact on how that individual's quality of life is perceived by others (Willer & Intagliata, 1984; Wolfensberger, 1991), the results of the study support institutionalization. For family members' in this study, the setting of choice was the institutional setting. In their views, this could be considered the normalized environment. As noted, many family members' reported that this environment offered their family member with the mental disability greater freedom of movement, safety, permanence, etc. It is worthy to note that many respondents made personal communication with the researcher, one of which was the eldest respondent in this study at 95 years of age. The general consensus was continued support of state-operated institutions. This further supports the literature that although community placements are a viable option for many, not all parents or family members of people with mental disabilities are enamored equally with the concepts of normalization. Therefore, the debate remains on which environment is best and what constitutes a normal environment.

To what extent do personal support variables (emotional, financial, social, physical/health and facility) impact family members' decision to maintain institutional placement?

1. Personal supports had an important influence on family members' decisions to maintain placement particularly with regards to facility and physical/health supports. These supports included the need for 24 hr. supervision, need for non-medical services,

need for more protected environment. Social supports was also very important included advice of doctors, trouble getting needed help to care for him/her, lack of supportive services in the community. Additionally, physical/health which included the difficulty of physical care of their mental disabled family member, illnesses in the family, trouble managing behaviors, health of family members, age of the family members and age of the mentally disabled person was significant in the family members decisions to maintain placement These findings suggest that the need for facility, social, and physical/health supports did play a role in determining family members' choices to maintain placement in a state-operated institution.

When completing an analysis of the findings through the lens of multiculturalism, several critical assumptions may be made. Given the cultural values of people of color, placement consideration may have affected the number of respondents due to history of care provided by this group in the natural family home setting. Additionally, these results could equally have been influenced by the class and socio-economic status of people of color with regards to access to institutions and information, thus, may potentially have affected current placement status.

Recommendations for Future Research

The following recommendations for future research are presented from findings of this study.

1. Qualitative studies with members of this population would be helpful in providing an in-depth follow-up through interviews on placement decisions as opposed to a mailed questionnaire.

2. Studying family members’ by class and culture may provide useful research findings to determine if significant differences exist among the groups access to state institutional services.
3. This study researched variables family members’ considered in their decisions to both seek and or maintain placement in a state-operated institution. Additionally, the research sought to examine respondents’ reasons for choosing placement. Future studies may research a larger population of similar individuals to see if there will be significant differences in responses.
4. Future studies may seek to research populations of family members’ in regards to their decisions to maintain community placements to see if there are significant differences than those that maintain placement in a state-operated institution.
5. This study sought information on what degree emotional, physical/health, financial, social, and facility supports play in the decisions to maintain placement. Since financial supports did not reflect an adequate number of questions, future research that provides more questions on finances may provide some useful information in terms of its impact on decision making regarding placement.

6. Future studies may seek to research siblings that serve as primary family members of residents in state-operated institutions to poll their views on care provision for a family member with a mental disability.
7. Further studies should be done to research periods of time which family members with mental disabilities have stayed at the state-operated institutions to see if level of functioning has changed over time.

REFERENCES

Allen, M.K. (1972). Persistent factors leading to application for admission to a residential institution. *Mental Retardation, 10*(1), 25-38.

American Association on Mental Retardation. (2002). *Mental retardation: Definition, classification, and systems of supports* (10th ed.) Washington, DC: Author.

Anderson, L.L., Lakin, K.C., Mangan, T.W., & Prouty, R.W. (1998). State institutions: Thirty years of depopulation and closure. *Mental Retardation*, *36*(6) 431- 443.

Anderson, L., Prouty, R., & Lakin, K.C. (1999). Closure of large state facilities and reductions of resident populations. *Mental Retardation, 37*(6), 509-10.

Atthowe, J. M., & Vitello, S. J. (1982). *Deinstitutionalization: Family reaction and involvement.* Unpublished manuscript, College of Medicine and Dentistry of New Jersey, Rutgers Medical School, New York.

Balla, B. A., Butterfield, E. G., & Zigler, E. (1974). Effects on institutionalization on retarded children: A longitudinal cross-institutional investigation. *American Journal of Mental Deficiency*, *78*, 530-547.

Bank-Mikkelsen, N. E. (1969). A metropolitan area in Denmark: Copenhagen. In R. Kugel & W. Wolfensberger (Eds.). *Changing patterns in residential services for the mentally retarded* (pp. 227-254). Washington, DC: U.S. Government Printing Office.

Baumeister, A. A. (1982). From: Cavalier and McCarver on *Wyatt v. Stickney*: A clarification. *Mental Retardation*, *20*, 10-141.

Baumeister, A. A., & Butterfield, E. (1970). *Residential facilities for the mentally retarded.* Chicago, IL: Aldine Publishing Co.

Bellamy, T. G., Newton, S. J., LeBaron, N. M., & Horner, R. H. (1990). Quality of life and lifestyle outcomes: A challenge for residential programs. In R. Schalock (Eds.) *Quality of life: Perspectives and issues* (pp.85-92). Washington, DC: American Association on Mental Retardation.

Best-Sigford, B., Bruininks, R. H., Lakin, K. C., Hill, B. K., & Heal, L.W. (1982). Resident release patterns in a national sample of public residential facilities. *American Journal of Mental Deficiency, 87*(2), 130-140.

Blacher, J. (1990). Assessing placement tendency in families with children who have severe handicaps. *Research in Developmental Disabilities, 11*, 349-359.

Black, M., Cohn, J., Smull, M., & Crites, L. (1985). Individuals and family risk factors associated with risk of institutionalization of mentally retarded adults. *American Journal of Mental Deficiency*, *90*, 271-276.

Black, M., Molaison, V., & Smull, M. (1990). Families caring for a young adult with mental retardation: Service needs and urgency of community living request. *American Journal of Mental Deficiency*, *95*(1), 32-39.

Blatt, B., & Kaplan, F. (1967). *Christmas in purgatory: A photographic essay on mental retardation*. Boston, MA: Allyn & Bacon.

Bogdan, R., Biklen, D., Blatt, B., & Taylor, S. T. (1981). Handicap prejudice and social science research. In H. C. Haywood, & J. R. Newbrough, (Eds.), *Living* *environments for developmentally retarded persons* (pp. 235-247). Baltimore, MD: University Park Press.

Borthwick-Duffy, S., Eyman, R., & White, J. (1987). Client characteristics and residential placement patterns. *American Journal of Mental Deficiency*, *92*, 24 30.

Braddock, D. (1990). *The state of the state in developmental disabilities*. Baltimore, MD: Paul H. Brooks Publishing Co.

Braddock, D. (1991). *Issues in the closure of state schools in Texas: A briefing paper*. Illinois University Affiliated Program in Developmental Disabilities, The University of Illinois at Chicago.

Braddock, D., & Heller, T. (1985). The closure of mental retardation institutions II: Implications. *Mental Retardation*, *23,* 222-229.

Braddock, D., & Mitchell, D. (1990). *Residential services and developmental disabilities in the United States: A national survey of staff compensation, turnover, and related issues.* Washington, DC: American Association on Mental Retardation.

Brockmeier, W. (1975). Attitudes and opinions of relatives of institutionalized mentally retarded individuals toward institutional and non-institutional care and training. University of Nebraska, doctoral dissertation. *Dissertation Abstracts International, 35*, 5163A.

Bruininks, R. H. (1990). There is more that a zip code to change in services. *American Journal on Mental Retardation, 90*, 13-15.

Cavalier, A. R., & McCarver, R. B. (1981). *Wyatt v. Stickney* and mentally retarded individuals. *Mental Retardation, 19*, 209-214.

Colombatto, J., Isett, R., Roszkowski, M., Spreat, S., D'Onofrio, A., & Alderfer, R. (1982). Perspectives on deinstitutionalization. *Education and Training of the Mentally Retarded*, *17*(1), 6-11.

Conroy, J. W. (1984). 1984 *monitoring report for 1611 people living at state centers.* (Technical report ARG 84-6.) Philadelphia, PA: Temple University, Developmental Disabilities Center.

Conroy, J. W. (1985). Reactions to deinstitutionalization among parents of mentally retarded persons. In R.H. Bruininks, & K.C. Lakin, (Eds.), *Living and learning in the least restrictive environment*. (pp. 141-152). Baltimore, MD: Paul H. Brookes Publishing.

Conroy, J. W. (1987). 1987 survey of the families of the people who live at Georgia Retardation Center and Bainbridge State Hospital: An interim report of the GRC Alternatives Feasibility Study. Report to the Georgia Department of Human Resources. Philadelphia, PA: Conroy & Feinstein Associates.

Coucouvanis, K. K., Lakin, K.C., Prouty, R., & Webster, A. (2006). Reductions continue in average daily populations of large state facilities; nearly 70% decrease between 1980 and 2005. *Mental Retardation*, *44*(3), 235-238.

Crissey, M. S., & Rosen, M. (1986). *Institutions for the mentally retarded: A changing role in changing times.* Austin, TX: PRO-ED.

Davies, S., & Ecob, K. (1959). *The mentally retarded in society*. New York, NY: Columbia University Press.

Doll, E.A. (1962). Trends and problems in the education of the mentally retarded, 1800-1940. *American Journal of Mental Deficiency, 72*, 175-183.

Downey, K. J. (1965). Parents' reasons for institutionalizing severely mentally retarded children. *American Journal of Mental Deficiency, 76,* 692- 698.

Eyman, R., O'Conner, G., Tarjan, G., & Justice, R. (1972). Factors determining residential placement of mental retarded children. *American Journal of Mental Deficiency, 76,* 692-698.

Felce, D., Thomas, M., DeKock, U., Saxby, H., & Repp, A. (1985) An ecological comparison of small community based houses and traditional institutions-II. *Behavior Research & Therapy, 23*, 337-348.

Ferguson, R. (1978). *The other side of the coin*. Paper presented at the annual meeting of the American Association on Mental Deficiency, Denver, CO.

Ferrara, D. (1979). Attitudes of parents of mentally retarded children toward normalization activities. *American Journal of Mental Deficiency, 84*, 145-151.

Fotheringham, J.B., Skelton, M., & Hoddinott, B.A. (1972). The effects on the family of the presence of a mentally retarded child. *Canadian Psychiatric Association Journal, 17*, 283-290.

Frohboese, R., & Sales, B. D. (1980). Parental opposition to deinstitutionalization. *Law and Human Behavior, 4*, 1-87.

Gall, M.D., Gall, J.P., & Borg, W. R. (2003). *Educational research: An introduction* (7th ed.). Boston, MA: Allyn and Bacon.

Gaver, K. D. (1975). Mental illness and mental retardation: The history of state care in Texas. *Impact*, *5*(2), 20-32.

Gorham, K. A. (1975). A lost generation of parents. *Exceptional Children*, *3*, 521-525.

Graliker, B.V., & Koch, R. A. (1965). A study of factors influencing placement of retarded children in a state residential institution. *American Journal of Mental Deficiency*, *69*, 553-559.

Griffith, R. G. (1986) Institutions: Are they legal? In M.S. Crissey, and M. Rosen (eds.) *Institutions for the mentally retarded: A changing role in changing times* (pp.49 61). Austin, TX: PRO Ed.

Grob, G. N. (1995). The paradox of deinstitutionalization. *Society*, *32,* 51-60.

Hayden, M. F. (1998). Civil rights litigation for institutionalized persons with mental retardation: A summary. *Mental Retardation*, *36*, 75-83.

Hill, R. (1958). Generic features of families under stress. *Social Casework, 39*, 139-150.

Hill, B. K., Lakin, K.C., & Bruininks, R. H., (1984). Trends in residential services for people who are mentally retarded: 1977-1982. *Residential Trends, 9*(4), 243 250.

Hobbs, N. (1964). A comparison of institutionalized and non-institutionalized mentally retarded. *American Journal of Mental Deficiency*, *69*, 206-210.

Huefner, D. S. (2000). *Getting comfortable with special education law: A framework for working with children with disabilities.* Norwood, MA: Christopher-Gordon Publishers, Inc.

Janicki, M., Krauss, M., & Seltzer, M. (1988). *Community residences for persons with developmental disabilities: Here to stay*. Baltimore, MD: Brookes Publishing Co.

Jones, D. R., & Allee, S. (2002). The handbook of Texas online: Texas Department of Mental Health and Mental Retardation. Retrieved from http://www.tsha.utexas.edu/handbook/online/articles/ view/TT.mctvf.html.

Kanner, L. (1964). *History of the care and study of the mentally retarded*. Springfield, IL: Charles C. Thomas Publisher.

Keating, D., Conroy, J., & Walker, S. (1980). *Family impacts baseline: A survey of families of residents of Pennhurst* (Pennhurst Longitudinal Study Technical Report PC-8-3). Philadelphia, PA: Temple University Developmental Disabilities Center.

Kirk, S. A., & Gallagher, J. J. (1986). *Educating exceptional children* (5th ed.). Boston, MA: Houghton Mifflin.

Klaber, M. (1969). The retarded and institutions for the retarded: A preliminary research report. In S. B. Sarason and J. Doris (Eds.), *Psychological problems of mental deficiency,* New York, NY: Harper & Row.

Kleinberg, J., & Galligan, B. (1983). Effects of deinstitutionalization on adaptive behavior of mentally retarded adults. *American Journal of Mental Deficiency*, *88*, 21-27.

Krishef, C. H. (1983). *An introduction to mental retardation*. Springfield, IL: Charles C. Thomas Publishing.

Lakin, K.C. (1979). *Demographic studies of residential facilities for mentally retarded people: A historical review of methodologies and findings.* Minneapolis, MN: University of Minnesota, Research and Training Center on Community Living Institute on Community Integration.

Lakin, K.C. (2002, October). *Access to support for community lives, homes and social \ roles: A review of national goal, current knowledge and recommendations for a future research agenda to assist in achieving our national goals.* Paper presented at the Invitational Conference on National Goals, the State-of Knowledge and a Future Research Agenda on Intellectual and Developmental Disabilities, Washington, DC.

Lakin, K.C, Smith, J., Prouty, R., & Polister, B. (2001). State institutions during the 1990s: Changes in the number of facilities, average daily populations, and expenditures between fiscal years 1991 and 2000. *Mental Retardation, 39*(1), 72-75.

Landesman, S., & Vietze, P. (1987). *Living environments and mental retardation*. Washington, DC: American Association on Mental Retardation.

Larson, S. A., & Lakin, K.C. (1989). *Parent attitudes about their daughter's or son's residential placement before and after deinstitutionalization.* (Policy Research Brief, Vol. 1, No. 2) Minneapolis, MN: University of Minnesota, Research and Training Center in the Institute on Community Integration.

Larson, S. A., & Lakin, K. C., (1991). Parent attitudes about residential placement before and after deinstitutionalization: A research synthesis. *Journal of the Association for Persons with Severe Handicaps*, *16*(1), 25-38.

Latib, A,. Conroy, J., & Hess, C. M. (1984). Family attitudes toward deinstitutionalization. In N. Ellis, & N. Bray (Eds.). *International Review of Research in Mental Retardation*, *12*, 67-93. New York, NY: Academic Press.

Lazarus, R. S. (1966). *Psychological stress and the coping process.* New York, NY: McGraw-Hill.

Meyer, R. (1980). Attitudes of parents of institutionalized mentally retarded individuals toward deinstitutionalization. *American Journal of Mental Deficiency*, *85*, 184 187.

McCubbin, H. L. (1979). Integrating coping behavior in family stress theory. *Journal of Marriage and the Family*, *41*, 237-244.

Mitchell, G. J. (1988). *Medicaid Home and Community Quality Services Act of 1987: Hearing before the Subcommittee on Health of the Committee on Finance on S. 1673.* Washington, DC: U.S. Government Printing Office.

Nirje, B. (1969). The normalization principles and human management implication. In R. Kigel & W. Wolsensberger (Eds.) *Changing patterns in residential services for the mentally retarded.* Washington, DC: President’s Committee on Mental Retardation.

Noll, S. (1995) *Feebleminded in our midst.* Chapel Hill: The University of North Carolina Press.

Noll, S., & Trent, J. (2004). *Mental retardation in America. A historical reader*. New York, NY: University Press.

Novak, A. R. (1976). Backlash to the deinstitutionalization movement. In A. Novak & I. Heal (Eds.) *Integration of developmentally disabled individuals into the community* (pp. 181-189). Baltimore, MD: Paul H. Brooks Publishing Co.

Payne, J. E. (1976). The deinstitutionalization backlash. *Mental Retardation, 3*, 43-45.

Pennhurst State School & Hospital v. Halderman: 446 F. Supp. 1295 (1977).

Prouty, R., & Lakin, K. C. (1997). *Residential services for persons with developmental disabilities: Status and trends through 1995* (Rep. No. 48). Minneapolis, MN: University of Minnesota, Institute on Community Integration.

Roos, P. (1976). *Trends in residential institutions for the mentally retarded. Trends in education series.* Columbus, OH: University Council for Educational Administration.

Rosen, M. (1994). Empowerment: A two-edged sword. *Mental Retardation*, *31*(1), 773-74.

Rosen, M., Clark, G. R., & Kivitz, M. S. (1976). *The history of mental retardation*. Baltimore, MD: University Park Press.

Rotholz, D. A., & Massey, P. S. (1996). Comparison of states' utilization of large residential settings for persons with mental retardation. *Mental Retardation*, *35*(5) 303-311.

Saenger, G. (1960). *The adjustment of severely retarded adults in the community*. Albany, NY: New York State Interdepartmental Health Resources.

Sattler, J. M. (1988). *Assessment of children (3rd* ed). San Diego, CA: Jerome M. Sattler Publishing.

Schalock, R. L. (1990). *Quality of life: Perspectives and issues* (pp141-148). Washington, DC: American Association on Mental Retardation.

Scheerenberger, R.C. (1976). *Public residential services for the mentally retarded, 1976.* National Association of Superintendents for Public Residential Facilities for the Mentally Retarded.

Scheerenberger, R.C. (1983). *A history of mental retardation*. Baltimore, MD: Paul H. Brooks Publishing Co.

Shellhaass, M., & Nihira, K. (1969). Factor analysis of reasons retardates are referred to an institution. *American Journal of Mental Deficiency*, *74*, 171-179.

Sherman, B. R. (1988). Predictors of the decision to place developmentally disabled family members in residential care. *American Journal of Mental Deficiency*, *92*(4), 344- 351.

Sherman, B., & Cocozza, J. (1984). Stress in families of the developmentally disabled: A literature review of factors affecting the decision to seek out-of-home placement. *Family Relations*, *33*, 95-103.

Shumaker, S. A., & Brownell, A. (1984). Toward a theory of social support: Closing conceptual gaps. *Journal of Social Issues, 40,* 11-36.

Skeels, H. M. (1966). *Adult status of children with contrasting early life experience*. Monographs of the Society for Research in Child Development, 31 (No.105).

Spreat, S., Telles, J., Conroy, J., Feinstein, C., & Colombatto, J. (1987). Attitudes of families toward deinstitutionalization: A national survey. *Mental Retardation, 5,* 267-274.

SPSS, Inc. (2003). *SPSS user's guide: A complete guide to SPSS language and operations.* New York, NY: McGraw Hill.

Stedman, D. J. (1977). Introduction. In J.L. Paul., D. J. Stedman., & G. Neufeld (Eds.). *Deinstitutionalization: Program policy development.* Syracuse, NY: Syracuse University Press.

Tausig, M. (1985). Factors in family decision making about placement for developmentally disabled individuals. *American Journal of Mental Deficiency, 89*(4), 352-361.

Trent, Jr., J. (1994). *Inventing the feeble mind: A history of mental retardation in the United States.* Berkeley, CA: University of California Press.

Turning points: History of the Texas Department of MHMR: 1856-1989. Austin, TX: Public Information Office.

U.S. Department of Justice Civil Rights (1999). Civil rights of institutionalized persons. Retrieved June 29, 2005 from http://www.usdoj.gov/crt/split/cripa.htm.

Vargas, T. (1987). *Chronology of the TDMHMR lawsuits.* House Research Organization, Texas House of Representatives. Austin, TX.

Willer, B. W., Intagliata, J. C., & Atkinson, A. C. (1978). *Deinstitutionalization as a crisis event for families of mentally retarded persons.* Unpublished manuscript, Division of Community Psychiatry, Department of Psychiatry, State University of New York at Buffalo, NY.

Willer, B.W, Intagliata, J. C., & Atkinson, A. C. (1979). Crisis for families of mentally retarded persons including the crisis of deinstitutionalization. *British Journal of Mental Subnormality, 2,* 2-7.

Willer, B.W, & Intagliata, J. (1984). *Promises and realities for mentally retarded citizens: Life in the community*. Baltimore, MD: University Press.

Wolf, L. C., & Whitehead, P. C. (1975). The decision to institutionalized retarded children: Comparison of individually matched groups. *Mental Retardation, 13,* 3 7.

Wolfensberger, W. (1972). *Normalization*: *The principle of normalization in human services*. Toronto, Canada: National Institute on Mental Retardation.

Wolfensberger, W. (1991). *A brief introduction to social role valorization as a high order concept for structuring human services.* Syracuse, NY: Training Institute for Human Service Planning, Leadership and Change Agency (Syracuse University).

Wolfensberger, W., & Tullman, S. (1991). A brief outline of the principle of normalization. In M.B. Eisenberg & R.L. Glueckauf (Eds.), *Empirical approaches to the psychosocial aspects of disability.* (pp. 202-215). New York, NY: Springer Publishing Company.

Wyatt v. Stickney: 344 F. Supp. 373 (M.D. Ala. 1972).

APPENDIXES

APPENDIX A

PERMISSION LETTER

Alex D. Colvin
701 Bormann St.
Brenham, Texas 77833
(979) 836-0553

March 10, 2006

Mr. Al Barrera, Superintendent
Southwood State School
2001 Preston St.
Southwood, Texas, 77460

Dear Mr. Barrera:

The purpose of this letter is to seek permission to have your state school participate in a research study entitled, "Variables Influencing Family Members' Decisions Regarding Continued Placement of Family Members with Mental Disabilities in a State-Operated Institution." This study is part of my doctoral dissertation requirements for the Doctor of Philosophy degree in the Department of Teaching, Learning and Culture at Texas A&M University in College Station, Texas. The study is being conducted to examine variables family members use regarding continued placement of their family members in state-operated institutions. The study will further examine the impact of each personal support variable of physical-health, emotional, financial, social supports and facility of family members on continued placement of a family member with a mental disability.

The population involved will include 150 family members (mother, father, sister, brother, aunts, uncle, etc.) of individuals residing at one state school (Southwood State School) in Texas. Participants will be asked to complete a questionnaire mailed to them. The information collected in this study is confidential and names will not be used. Results will be reported by overall numbers and generic letters in order to guarantee absolute confidentiality.

Thank you for granting permission to complete this study on this campus.

____
Alex D. Colvin, Doctoral Candidate
Department of Teaching, Learning, and Culture
Texas A&M University
College of Education and Human Development

____
Dr. Patricia J. Larke, Doctoral Committee Chair
Department of Teaching, Learning, and Culture
Texas A&M University
College of Education and Human Development

I have read the above statements and agree to have this campus participate in this research study regarding variables influencing family members' continued placement of family members with a mental disability in one state-operated institution.

__________________________ __________________________
Superintendent's Signature Date

APPENDIX B

COVER LETTER TO INSTRUMENT

March 10, 2006

Dear Family Members:

Many of you have received this questionnaire entitled: “Survey of Caregivers’ Decisions Regarding Placement”. If you received this questionnaire, please do not become alarmed. This is part of a research project I have given him permission to conduct here at Southwood State School. The student conducting this research project is a young man named Alex Colvin. Mr. Colvin is a doctoral student in the Department of Teaching, Learning and Culture at Texas A&M University. He is also employed at Brenham State School as a Residence Director.

The purpose of his research is to determine, “Variables Influencing Family Members’ Decisions Regarding Continued Placement of Family Members with Mental Disabilities in a State-Operated Institution.” The study will examine the impact of five variables: physical-health, emotional, financial, social supports and facility of family members on continued placement of a family member.

Please be advised, this research project is not intended to get your personal views on placement for the purpose of gathering information on how state schools can be closed. The research project is simply to help this student obtain meaningful information on caregiver choice to complete his dissertation, nothing more.

If you agree to participant you are asked to complete the enclosed survey questionnaire. Your participation is strictly voluntary and your responses will be confidential. Also, neither your name nor any information identifying you will be used or associated with your responses or this study. To ensure absolute confidentiality, Southwood State School staff has mailed this survey to you at Mr. Colvin’s expense. This will ensure that Mr. Colvin have no access to any of your personal information (addresses, telephone numbers, identifying information, etc.).

Please take a few minutes to respond to the questions on the questionnaire. You should be able to complete the questionnaire within 15 minutes. Once you have completed it, simply return the questionnaire in the enclosed postage paid envelope.

Once this research project is completed, if you are interested data from this project will be made available to you if you desire.

I appreciate your help in this effort and thank you again for your assistance. If you have any questions, please do no hesitate to contact us.

Sincerely,

____

Al Barrera, MA
Superintendent
Southwood State School

Enclosure

APPENDIX C

FOLLOW UP REMINDER POST CARD

April 11, 2006

Dear Family Members:

On March 21, 2006, you were mailed a questionnaire designed to obtain information from you on placement choice.

Your input is vital to the success of this study. If you have not had time to complete the questionnaire, please take a few minutes to do so, and return your completed questionnaire to us by April 28, 2006. If you are in need of another survey please call Gloria Henrichsen at Southwood State School at (281) 344- 4465 and she will mail you one.

Keep in mind this project is not intended for the purpose of state school closure. Your responses will be confidential, and neither your name nor any information identifying your will not be associated with your responses. Thank you for your time and assistance in this important research.

Sincerely,

Alex Colvin, Student Researcher

APPENDIX D

CORRESPONDENCE GRANTING PERMISSION TO USE INSTRUMENTS

----- Original Message -----
From: SSpreat@woods.org
To: alexandamy@symet.net
Sent: Tuesday, September 06, 2005 8:41 AM
Subject: RE: Information request

Use, modify, adapt, etc. Use it as you see necessary. I haven't looked at the project in a number of years, but I guess we had no reliability or validity data on the instrument.

Good luck with your project.

-----Original Message-----
From: Tausig, Mark B [mailto:mtausig@uakron.edu]
Sent: Friday, December 02, 2005 12:56 PM
To: Colvin, Alex
Subject: RE: Requesting permission to use your instrument?

Alex:

You have my permission to use this survey instrument in any manner you wish. I no longer have any information regarding validity and reliability of the measures.

Mark Tausig, Ph.D.

Department of Sociology

University of Akron

Akron, OH 44325-1905

330.972-6914

330.972.5377-fax

----- Original Message -----
From: "Barry R. Sherman" <brs02@health.state.ny.us>
To: "Alex Colvin" <alexandamy@symet.net>
Sent: Tuesday, September 05, 2006 7:33 AM
Subject: Re: Fw: Information request

Alex,

You have permission to use the survey as long as the published article is properly cited in the dissertation. Also, I would greatly appreciate receiving a copy of your completed work. All the best and good luck.

Barry R. Sherman, Ph.D.

New York State Department of Health

Office of Minority Health

Associate Professor, Health Policy,

Management and Behavior,

University at Albany, School of Public Health

780 Corning Tower, Albany, New York 12237

PH: (518) 474-2180; FAX: (518) 474-4695

APPENDIX E

INSTRUMENT

SURVEY OF CAREGIVERS' DECISIONS REGARDING PLACEMENT

SURVEY OF CAREGIVERS' DECISIONS REGARDING PLACEMENT

Please take a moment to complete this survey regarding caregivers' placement of family members in a long-term residential care facility. Your opinion is important. Upon completion of the survey, please return it in the self-addressed, stamped envelope. Thank you

Part I - Personal Characteristics

1. Age __________

2. Gender ① Male ② Female

3. What is your relationship to the person who has a developmental disability? (Bubble one response)

① Mother ② Mother and Father (responding together) ③Sister
④Father ⑤Brother ⑥Other: (specify)

4. Marital status at time of initial placement (Bubble one response)

○ Married ○ Divorced ○ Separated ○ Widowed ○ Never Married ○ Other (specify)

5. Current marital status (Bubble one response)

○ Married ○ Divorced ○ Separated ○Widowed ○ Never Married ○ Other (specify)

6. Ethnicity (Bubble one response)

① European American
② African American
③ Hispanic American
④ Native American
⑤ Asian American
⑥ Other _________ (specify)

7a.Educational Background (Fill highest level completed.)	7b. Educational Background of Spouse (Skip if no spouse)
① Grade school	① Grade School
② Some high school	② Some high school
③ Completed high school	③ Completed high school
④ Some College, no degree	④ Some college, no degree
⑤ Junior or business college degree	⑤ Junior or business college degree
⑥ College degree (4 year)	⑥ College degree (4 year)
⑦ Graduate school	⑦ Graduate school

8. Approximate yearly family income (Bubble appropriate response)

① Under $10,000
②$10,000 – 25,000
③$25,000 – 40,000
④$40,000 – 55,000
⑤$55,000 – 70,000
⑥$70,000 – 85,000
⑦$85,000 – 100,000
⑧over $100,000

9. Do you receive any of the following forms of financial assistance? (Bubble all that apply.)

○Aid to Families with Dependent Children (AFDC) ○Family/Friends

○Supplemental Security Income (SSI) ○Unemployment Insurance

○Medicaid/Medicare ○Teacher Retirement System (TRS)

○Pension, RR Retirement or Veterans. Benefits ○Social Security

○Disability Benefits ○Assistance with Housing ○None ○Other

Part I - Personal Characteristics (continued)

10. What are your family members identified developmental disabilities? (Bubble all that apply.)

①Autism
②Cerebral Palsy
③Seizure Disorder
④Mental Retardation
⑤ Other Neurological Impairment
⑥ Mental Health Disorder
⑦Other______ (Specify)

11. What is your family member's level of mental retardation? (Bubble one response)

①Not retarded
②Mild mental retardation
③Moderate mental retardation
④Severe mental retardation
⑤Profound mental retardation
⑥Not known

12. Other than your family member with a disability, is there any other person(s) living in your household who has significant health or emotional problems?

Relationship to Family member with a disability	Age	Physical	Emotional	Retardation or developmental disabilities	Drug use or Alcohol use
_____________	____	_________	_________	____________	________
_____________	____	_________	_________	____________	________
_____________	____	_________	_________	____________	________

13. What specific circumstances or events caused you to seek placement for your family member who is disabled in a long-term residential care facility? (Bubble all that apply)

○ They couldn't live independently
○ Behavior Problems
○ Could receive more intensive care or specialized programs
○Advice of physician or other medical specialist(s)
○Financial Problems
○Legal Problems
○Death or illness of primary caretaker in family
○Health problems
○Disruption of family life
○ Couldn't get needed services in the home
○ Other: ___________ (specify)

14. Would you tell us why you choose to maintain placement for your family member who is disabled in a long-term residential care facility? (Bubble all that apply)

○ Lacks Independent Living Skills
○ Behavioral Services
○ Could receive more intensive care or specialized programs
○ Advice of Physician or other professional(s)
○ Medical Services
○ More Freedom of movement
○ Level of disability
○ Death or illness of primary caretaker in family
○ Security of institution
○Other: ___________
○ Health problems
○ Disruption of family life
○ Can not get needed services in the home
○ Age of caregiver
○Other: ________

Part II- Placement Survey

15. The following is a list that many consider in their choices **to seek placement** of their family members in a long-term residential care facility.

How important were the following in the decision to place your relative in a long-term residential care facility? Please indicate level of importance that each variable had on your decision (Bubble level of importance).

	Not Important	Slightly Important	Somewhat Important	Important	Very Important
1. Difficulty of physical care	①	②	③	④	⑤
2. Advice of doctor or other professional	①	②	③	④	⑤
3. Money problems	①	②	③	④	⑤
4. Illness in family	①	②	③	④	⑤
5. Problems in the marriage	①	②	③	④	⑤
6. Difficult for other children in family	①	②	③	④	⑤
7. Hurt relationship with relatives and friends	①	②	③	④	⑤
8. Pressure from relatives or friends	①	②	③	④	⑤
9. Relatives need for medical care	①	②	③	④	⑤
10. Need for non-medical services (work, school, speech, toileting, etc.)	①	②	③	④	⑤
11. Need for a more protected place/secure environment	①	②	③	④	⑤
12. Trouble getting help to care for him/her	①	②	③	④	⑤
13. Trouble managing his/her behavior	①	②	③	④	⑤
14. Your health status	①	②	③	④	⑤
15. Your age	①	②	③	④	⑤
16. Your relatives age	①	②	③	④	⑤
17. 24 hr supervision	①	②	③	④	⑤
18. Supportive service in the community	①	②	③	④	⑤
19. Other ________	①	②	③	④	⑤

Part II- Placement Survey (continued)

16. The following is a list that many consider in their choices **to maintain placement** of their family members in a long-term residential care facility.

How important were the following in your decision to maintain placement of your relative in a long-term residential care facility? Please indicate level of importance that each variable had on your decision (Bubble level of importance).

	Not Important	Slightly Important	Somewhat Important	Important	Very Important
1. Difficulty of physical care	①	②	③	④	⑤
2. Advice of doctor or other professional	①	②	③	④	⑤
3. Money problems	①	②	③	④	⑤
4. Illness in family	①	②	③	④	⑤
5. Problems in the marriage	①	②	③	④	⑤
6. Difficult for other children in family	①	②	③	④	⑤
7. Hurt relationship with relatives and friends	①	②	③	④	⑤
8. Pressure from relatives or friends	①	②	③	④	⑤
9. Relatives need for medical care	①	②	③	④	⑤
10. Need for non-medical services (work, school, speech, toileting, etc.)	①	②	③	④	⑤
11. Need for a more protected place/secure environment	①	②	③	④	⑤
12. Trouble getting help to care for him/her	①	②	③	④	⑤
13. Trouble managing his/her behavior	①	②	③	④	⑤
14. Your health status	①	②	③	④	⑤
15. Your age	①	②	③	④	⑤
16. Your relatives' age	①	②	③	④	⑤
17. 24 hr supervision	①	②	③	④	⑤
18. Supportive service in the community	①	②	③	④	⑤
19. Other ________	①	②	③	④	⑤

Part III- Facility Survey

17. How well has the long-term residential care facility done in providing these things for your family member (Bubble level of satisfaction)

	Very Dissatisfied	Somewhat Dissatisfied	Neutral	Somewhat Satisfied	Very Satisfied
1. Recreation (trips, sports, arts & crafts)	①	②	③	④	⑤
2. Learning/improving self-care (grooming, hygiene, dressing, etc.)	①	②	③	④	⑤
3. Keeping him/her active and busy	①	②	③	④	⑤
4. Medical Services (physical therapy, dental, nursing)	①	②	③	④	⑤
5. A secure and permanent home	①	②	③	④	⑤
6. Learning/ improving social skills	①	②	③	④	⑤
7. Getting rid of problem Behaviors	①	②	③	④	⑤
8. Physical comfort	①	②	③	④	⑤
9. Learning/improving basic reading, writing, and use of numbers	①	②	③	④	⑤
10. Protection from harm	①	②	③	④	⑤
11. Preparation and training for work	①	②	③	④	⑤
12. Quality staffing	①	②	③	④	⑤
13. Active treatment (daily training)	①	②	③	④	⑤
14. Professional Services (Psychological, QMRP Social Work)	①	②	③	④	⑤
15. Freedom of movement	①	②	③	④	⑤

Thank you for your cooperation and assistance in completing this survey

VITA

Candidate:	Alex Don Colvin
Permanent Mailing Address:	701 Bormann Street, Brenham, Texas 77833
Degree:	Doctor of Philosophy
Education:	Prairie View A&M University (Social Work) from 1989 to 1993: Received B.A. degree in Social Work University of Houston (Social Work) from 1995 to 1997: Received M.S. degree in Social Work Texas A&M University (Curriculum & Instruction) from 2001 to 2006: Received Ph.D. degree in Curriculum & Instruction
Professional Experience:	Assistant Professor, Department of Social Work, Behavioral, and Political Sciences, Prairie View A&M University, Prairie View, Texas. 2006- present Residential Director, Texas Department of Aging and Disability Services, 4001 Hwy 36 South, Brenham, Texas. 2002 - 2006 Clinical Social Worker, Texas Mental Health and Mental Retardation, 4001 Hwy 36 South, Brenham, Texas. 1998 -2002 Individual Program Coordinator, Texas Mental Health and Mental Retardation, 4001 Hwy 36 South, Brenham, Texas, 1993 – 1998