

5-31-2001

Adult Children with Developmental Disabilities: The Impact on the Mothers

Tracy J. E Mitchell
Augsburg College

Follow this and additional works at: <https://idun.augsburg.edu/etd>



Part of the [Social Work Commons](#)

Recommended Citation

Mitchell, Tracy J. E, "Adult Children with Developmental Disabilities: The Impact on the Mothers" (2001). *Theses and Graduate Projects*. 291.

<https://idun.augsburg.edu/etd/291>

This Open Access Thesis is brought to you for free and open access by Idun. It has been accepted for inclusion in Theses and Graduate Projects by an authorized administrator of Idun. For more information, please contact bloomber@augburg.edu.

Adult Children with Developmental Disabilities: The Impact on the Mothers.

Tracy J.E. Mitchell

Submitted in partial fulfillment of the requirement for the degree of Master of Social Work

Augsburg College
Minneapolis, Minnesota

2001

**MASTER OF SOCIAL WORK
AUGSBURG COLLEGE
MINNEAPOLIS, MINNESOTA**

CERTIFICATE OF APPROVAL

This is to certify that the Master's Thesis of:

Tracy Jo-Erickson Mitchell

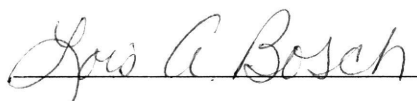
has been approved by the Examining Committee for the thesis requirement for the Master of Social Work degree.

Date of Oral Presentation: May 31, 2001

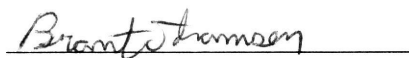
Thesis Committee:



Thesis Advisor: Laura Boisen



Thesis Reader: Lois Bosch



Thesis Reader: Brant Thomsen

DEDICATION:

I dedicate this study to all mothers, especially those who face the everyday challenge of having a child with a disability. Your strength, dedication, and perseverance for your children, regardless of the obstacles, never ceases to amaze me. Thank you for teaching us about the gift of unconditional love.

ACKNOWLEDGMENTS:

I would like to acknowledge my family and friends for helping me to survive this past year.

I would like to especially thank my husband, Jon, for ignoring the mess in our computer room and for being patient with my erratic sleep hours this past year.

My best friend, Lisa, who was there when I needed to cry about never getting done with my thesis or school!

My friends Brant and Rochelle and their daughters, Alyssa and Kiana, who managed to make me smile when no one else could.

My parents (Jim and Jan) and brother and sister (David and Molly) who have always encouraged me continue with my education.

Ron Hawkinson, my first (and the best) supervisor I had, who taught me who to be a social worker and how to ask the right questions. Thank you for being so supportive of me continuing with my education!

The staff at Chisago County. Thank you for tolerating and supporting me as I completed this long process of school.

Laura Boisen, my thesis advisor. Thank you for being the best professor and teacher I have ever had and for always giving me support and encouragement when I needed it. I have a tremendous amount of respect and admiration for you!

FINALLY.....

The mothers who participated in this research study. Thank you for allowing me to learn more about you and the lives of your children.

ABSTRACT

Adult Children with Developmental Disabilities: The Impact on the Mothers.

A Qualitative Study Which Explored the Process Mothers Endured in Raising a Child with a
Developmental Disability

Tracy J.E. Mitchell

June, 2001

ABSTRACT:

This qualitative study discussed and evaluated the affect adult children with developmental disabilities have upon their mothers. Extensive research has been done on children with disabilities and the impact upon their mothers, but little has been done regarding the adult children. Interviews were conducted with 5 mothers of adult children with developmental disabilities through the use of a snowball sample. The results indicated the mothers had mostly positive feelings towards their adult child. However, the study also found many of the mothers had unresolved grief issues regarding the raising of their adult child. The findings give implications to the social service field as to how social workers provide service to mothers of adult children with developmental disabilities.

TABLE OF CONTENTS

	Page Numbers:
Title Page.....	i
Certificate of Approval.....	ii
Dedication.....	iii
Acknowledgments.....	iv
Abstract.....	v
Table of Contents.....	vi
Chapter I: Introduction	
Overview.....	1
Chapter II: Review of the Literature	
Overview.....	3
Scope of the Problem.....	3
Timeline.....	4
Out of Home Placements.....	6
Futures Planning.....	7
Financial Issues.....	7
Positive Impacts.....	8
Search for a Cure.....	8
Siblings.....	9
Gaps in the Literature.....	10
Theoretical Orientation	11
Chapter III: Methodology	
Research Question and Design.....	14
Characteristics of the Sample Population.....	14
Subject Recruitment.....	15
Research Terminology.....	16
Instrument Development.....	17
Data Gathering.....	18
Data Analysis	19
Reliability and Validity.....	19
Limitations of the Study.....	20
Chapter IV. Findings	
Overview.....	21
Demographics of Participants.....	22

Theme One: Initial Reactions to Diagnosis.....	23
Initial Reactions.....	23
Thoughts and Feelings.....	24
Recommendations for Institutionalization.....	25
Search for a Cure.....	25
Spiritual Reaction.....	26
Sense of Pride.....	28
Summary.....	28
Theme Two: Impact on the Family.....	29
Family Adjustment.....	29
Relationship Between Mother and Spouse.....	29
Mother Adjustment.....	30
Summary.....	31
Theme Three: Out of Home Placement Issues.....	32
Past Experiences.....	32
Reasons to Keep Adult Child in Home of Origin.....	33
Reasons to Live Outside the Home of Origin.....	33
Summary.....	34
Theme Four: Hopes and Fears for Adult Children.....	35
Hopes.....	35
Fears.....	35
Least Helpful in Experiences.....	36
Most Helpful in Experiences.....	37
Summary.....	37
Chapter V. Discussion and Implications	39
Introduction.....	39
Impact.....	40
Stress and Personal Burden.....	41
Futures Planning.....	41
Initial Reactions.....	42
Policy Implications.....	43
Practice Implications.....	43
References.....	45
APPENDICES:	
Appendix A: Cover Letter to Arc.....	48
Appendix B: Consent form to participants.....	49
Appendix C: Demographics.....	53
Appendix D: Interview questions.....	54

CHAPTER I:

Introduction

Overview:

Historically, families of adult children with disabilities were expected to either place their child in a state hospital or care for their child without expectations of assistance from the state or county. Ineichen (1986) reported people with developmental delays may leave their home of origin at any point between infancy to adulthood. However, Ineichen (1986) went on to state many mothers would prefer their child with developmental disabilities live in a smaller local residence than a large mental hospital. He also found mothers felt hostility towards state mental hospitals and often preferred to keep their child at home rather than live in an institution.

In recent years, advocates for the disabled have supported legislation which would allow children and adults with disabilities to be supported in their home environment. (MN Statues, 1998, section 256B.0916) In addition, The National Information Center for Children and Youth with disabilities (2000) reports schools are now required by state and federal laws to provide special education services to children with disabilities. Seltzer (1992) stated fewer than 20% of individuals with developmental disabilities live outside the parental home. Therefore, more individuals with developmental disabilities are receiving services in their home of origin. This may be more positive for families but may also cause more stress for the family of origin.

Heller (1993) stated the aging mothers are often faced with future planning issues, especially concerns with who will resume the caretaking of the adult child upon the death of the mothers. Heller also reported the issue of futures planning for adults with disabilities is often the most stressful for mothers. The causes for the stress may vary. Many mothers may have

difficulty with the finality of placing their adult child outside the home. Some mothers may not believe that they can trust anyone else to care for their child. Regardless of the source of the fears, service providers would benefit from being made aware of the issues and stresses faced by mothers. The increased appreciation for the concerns of the mothers may enable providers of the consumers with disabilities to offer support to the mothers.

Therefore, all of the issues involved with being a mother of an adult child with a disability may impact the mother. Some of these issues may include futures planning as well as individuals with disabilities living longer and receiving more services. The issues of the mothers has not been evaluated or researched a great deal. Service providers need to be aware of the issues which concern the mothers, in order to effectively assist the adult child with disabilities. The research completed in this study will help alert providers to some of the fears, hopes and concerns the mothers of the individuals with disabilities may experience. Thus, the providers will be better able to serve the consumer and their families in a holistic manner.

CHAPTER II:

Review of the Literature

Overview:

This literature review will discuss the scope of the problem, of what individuals with developmental disabilities and their mothers face, as well as an historical overview of their treatment and how the diagnosis affects the mothers. The 1990 census reported 6.2 to 7.5 million individuals have a diagnosis of a developmental disability in the United States (Batshaw, 1997). The challenges individuals with developmental disabilities face, are quite varied. Some may be able to live independently, while others require total care. Regardless of the causes or the abilities of the individuals with developmental disabilities, the mothers are impacted by the diagnosis and ongoing care of the child with a developmental disability. The impact an adult child with a developmental disability has on the mothers will be reviewed in the literature review. In addition, implications for providers of individuals with developmental disabilities and their mothers as well as recommendations for future research will be discussed.

Scope of the Problem:

Hayden and Goldman (1996) reported two million people have a diagnosis of a developmental disability. However, as stated earlier, Batshaw (1997) reported 6.2 to 7.5 million individuals have a diagnosis of a developmental disability. In addition, The Arc (1982) reported 2.5 to 3 percent of the United States population has developmental disabilities. The literature states a vast majority of the individuals with disabilities live at home with their families. Historically, few services were available for individuals with disabilities, which often forced parents to relinquish the right to care for a child with a disability. Thus, people with disabilities were often placed in state hospitals or institutions regardless of the individuals or the family's

preferences. Essentially, families were given two options to cope with a member with a disability. The individual would either be placed in an institution or the family would care for the person without services or assistance from the state or county (Scheerenberger, 1987).

Historically, a great deal of shame was associated with a child with a disability was born. Koch and Koch (1974) noted 50 years ago, immediately following birth, any child who appeared to have abnormalities may have been destroyed or terminated. In addition, Scheerenberger, (1987) reported some physicians would allow severely disabled infants to die through omission of treatment. Fishley (1992) reviewed how society dealt with people with disabilities through a timeline.

1700's

In the 1700's, individuals who were believed to be a threat to society, were sent to a house of correction (Fishley 1992) . The house of correction was essentially a prison for the members of society who did not "fit" anywhere else.

1850-1920

Hollander (1986) stated in the mid 1800's, the first schools for "idiotic children" were built in France. The philosophy on the schools were to attempt to educate children through boarding schools. Fishley (1992) also stated that the thought at the time was to "make the deviant less deviant through education." However, Fishley (1992) went on to report that after approximately 30 years of attempting to educate people with disabilities, society began to believe that individuals with developmental delays were lazy. Therefore, people with disabilities were called degenerates and were placed on farm colonies to be self-sufficient. In addition, it was also determined that the more people who lived on the farm, the cost would decrease. Thus, Fishley (1992) reported approximately 500-600 people lived on the farm at one time, with

individuals sleeping on straw in a large one room building.

After approximately ten years of working on the farms, it was determined the individuals with disabilities were not producing enough to support themselves, so the farming was eliminated, yet the individuals continued to live in the farm buildings. The buildings were now called asylums. However, when the farm tasks were taken away from the residents, no other tasks were replaced.

1920-1960

Fishley (1992) stated in the 1920's the institutions were taken over by the state, yet the residents were not given any activities to do during the days and nights. The facilities were found to be overcrowded and residents were given little privacy (Scheerenberger, 1987). In addition, individuals with disabilities were often medicated to reduce aggressive behaviors.

1960-Present

In the 1960's, laws were passed to begin "deinstitutionalization" for the individuals in the state run institutions. The laws were passed in response to the court judgments which were handed down following lawsuits against the states by the families of individuals with disabilities. The Ohio senate passed a bill in 1967 to allow people to go home and receive service in their counties of origin (Fishley, 1992). However, many people had not seen their families in many years, and were taken away from their friends in the state hospitals. Fishley (1992) went on to report that through the 1970's up to the present, state and federal laws were passed, due to consumer demand, to allow individuals with disabilities to attend and participate in training programs to live more independently. In addition, families and individuals were also given options about living arrangements for the future.

In the past ten years, advocates and families of people with disabilities supported

normalization for people with disabilities, rather than institutionalization. Goodman (1978) reported normalization encouraged individuals with disabilities to achieve their goals and dreams. Many individuals with disabilities and their families would prefer to live and work within the community in a more “normal” lifestyle. Due to the demand for increased services, service providers have an increased need for research in the area of developmental disabilities and its impact upon the individuals and the mothers. Fullmer, Tobin and Smith (1997) noted the lack of research which assesses the needs of adult children with disabilities and the impact upon the mothers. Therefore, more information is needed regarding adult children with disabilities and the impact upon the mothers.

Due to the increased ability of services in the community, more people with disabilities are living in the home of origin. Haveman, van Berkum, Reijnders, and Heller (1997) reported a number of adult children live with their parents in the home of origin. As mentioned earlier, many mothers anticipate caring for their adult child throughout their life. Although services have improved and now allow families to remain intact, many mothers often delay in planning for out of home placements for their adult children.

Out of Home Placements

Engelhardt, Brubaker, and Lutzer (1988) reported mothers may be more willing to consider out-of-home placement if the physical cares and behaviors of the adult child are great. In addition, mothers may also wish to spare other family members from the taxing duties of caring for the individual with the disability. Griffiths and Unger (1994) concurred in their study, which found mothers do not wish to place the adult children with developmental and physical disabilities with other family members when the physical care was significant.

A significant issue which has received attention is the longer life span of all people,

including those with disabilities. Seltzer (1992) pointed out due to improved medical technology, individuals with developmental disabilities now have an average life expectancy, whereas in the past, were not expected to live past adulthood. Therefore, a number of people with developmental disabilities live with aging mothers.

However, many mothers did not anticipate the possibility their adult child with a developmental disability may outlive the mothers. Thus, many mothers encounter a crisis situation when families are ill prepared to place their adult child outside of the home when the caretaker is no longer able to care for the adult child.

Future Planning

A source of stress for mothers (Goodman, 1978; Hayden & Goldman, 1996; Kropf, 1997) is the care of the adult child following the death of the parent or inability to care for the adult child. As stated earlier, many mothers feel strongly about caring for their adult child throughout their life. However, many mothers are unwilling or unable to consider out-of-home placements for their adult children until a crisis occurs. Thus, many adults with developmental disabilities may suffer from "transfer trauma" when the individual is inappropriately placed and is required to move several times (Heller, 1988). The cause for the delay in planning is caused by a number of factors. Mothers may be more willing to consider out-of-home placement when the physical care of the adult child becomes too stressful to manage for the family members.

Financial Issues

In some cases, Heller and Factor (1993) reported the mother may rely upon the income of the person with a disability and cannot financially afford to place the adult child outside of the home. Frequently, an adult child is seen as a companion for elderly mothers and may assist mothers with household chores. Heller and Factor (1993) state many mothers felt a great deal of

benefit from being able to support the adult child in their home. In addition, as the mothers age and observe the death of their spouses, an adult child may be a source of financial as well as emotional support to the surviving parent.

Positive Impacts

Mothers perceive a higher functioning developmentally disabled adult child as having a positive impact upon the familial environment. Mothers and other family members are often reluctant to place the individual outside of the home if the person is seen as being helpful around the house and a companion to aging mothers.

In particular, mothers with an adult child with a diagnosis of Down Syndrome seem to have a more positive outlook upon the family member with a disability (Seltzer, Krauss & Tsunematsu, 1993). The explanation for the more positive outlook could be a number of factors. Seltzer et al., (1993) reported that individuals with Down Syndrome are considered to be higher functioning than people with other developmental disabilities. Therefore, people with a diagnosis of Down Syndrome are often able to complete their own personal cares and assist with some household chores. Possibly, a more significant factor in the outlook could be the increased awareness and widespread acceptance of Down Syndrome by society at large (Seltzer & Krauss, 1989). Another consideration in the rationale for the increased acceptance by the family is the unmistakable features of an individual with Down Syndrome. Thus, the mothers obtained a clear and accurate diagnosis immediately.

Search for a cure

Feelings of guilt and grief are common for mothers who have a child with a developmental disability. Frequently, the mothers will seek a cure and a cause for the impairment in hopes of improving the life of their child. Many mothers continuously seek a definitive cause and

diagnosis for the adult child's developmental disability. Often, mothers search for a reason for the disability due to guilt for possibly having been a carrier of a genetic trait which caused the developmental disability.

Siblings

Seltzer, Greenberg, Krauss, Gordon, and Judge (1997) noted most siblings of adults with developmental disabilities have positive feelings about their relationship with their sibling with developmental disabilities. However, the feelings of the siblings depends upon the functioning level and the amount of physical care and behaviors which the individual with a developmental disability had as the siblings grew up together. The feelings of the sibling may be more negative towards the person with a diagnosis of a developmental disability, if the individual with the disability had significant behavioral issues. As a family member, siblings are often expected to resume the care and responsibility for the person with a disability when the mothers are no longer able to continue to care for their adult child (Griffiths & Unger, 1994). However, as stated earlier, often the siblings are not included in the process of permanency planning for the adult child with developmental disabilities. However, different cultures may view the role of the siblings differently.

For example, Heller and Factor (1988) found African American families prefer the adult child with a developmental disability to remain in the family specifically to be cared for by a sibling. Griffiths and Unger (1994) also found a majority of the siblings chosen to assume the responsibility of caring for siblings are women. However, the issue of the sisters being chosen as caretakers is not unexpected as women in society are often in caretaker roles.

Gaps in the Literature

A number of factors are involved with an adult child with a developmental disability. The articles discussed how siblings are able to assist and provide support to the mothers and adult children throughout the life span of the adult child. However, the research did not include information or recommendations for service providers when mothers and families of adult children with developmental disabilities refuse or postpone permanency planning. A number of the authors discussed a need for mothers and families to be more involved in the planning process as well as be provided with more information regarding placement plans for the adult child (Heller & Factor, 1993).

More research is needed to assist the service providers in working with families who are hesitant to deal with placement issues. The service providers need direction and support, in order to assist mothers as well as the adult child. Planning for future residential placement and services would assist in preventing additional trauma upon the adult child when they are no longer able to continue to live in their home of origin with their parents or siblings.

Another issue which was not addressed in the research was the factors involved in the mothers decisions to postpone placement plans. Although several articles mentioned planning is delayed due to a lack of information, services and concerns for the individual's safety (Heller and Factor, 1988), it did not appear the research focused on the real issues which prevent mothers from permanency planning. Although it is unclear as to the source of the fear, research needs to be done to identify the cause of the apprehension. The service providers would greatly benefit from being aware of the issues which mothers face when addressing future plans. Therefore, the providers would be better able to assist the mothers in coping with their anxieties and relieving their fears for their adult child.

A number of approaches and research have been completed by authorities in the field to determine the needs and issues within a family in which a person with a disability is a member. The research completed was primarily qualitative in nature. In addition, the studies done were primarily through surveys and interviews in person or over the phone. However, it appeared the most successful research was done with the face-to-face interviews in less than two hours. The lack of success of some of the research projects could be due to the long length of surveys, which were sent to families or the drawn-out interviews, conducted with families.

Therefore, the question of how an adult child with developmental disabilities impacts the mothers continues to require research in order to assist the families, service providers, and the individuals with developmental disabilities.

Theoretical Orientation

A significant issue for the mothers is the amount of stress they are faced with in regards to the care of their adult children with developmental disabilities. A number of theories have been proposed which may assist the mothers in coping with the challenges of raising a child with disabilities. One of the theories focuses on the stages of grief and loss. The stages are similar to Elizabeth Kubler-Ross' theory of denial, anger, bargaining, depression and acceptance (Ziolko, 1991). However, the stages were adapted to address the needs of a mothers with a child with disabilities. Ziolko (1991) identified the stages as withdrawal or rejection, denial, fear and frustration, and adjustment. The mothers may initially withdraw from their child, when first learning of the disability, as they may not know how to cope with the disability and may not wish to bond with a child who may have been projected to have a short life span. Denial will often cause mothers to seek out causes or cures for the diagnosis. The fear and frustration stage may last for many years and may never end for some mothers. The final phase of adjustment begins

when mothers accept services and assistance for their children. Although the mothers may accept services and programs as inevitable, they may never escape the fear of the future for their child.

A significant impact upon mothers with a child with a developmental disability is the lifelong sadness, grief and loss issues which continue long after the individual has become an adult (Goodman, 1978). The individual will most likely be unable to obtain complete self-sufficiency and may always be dependent upon someone else. Goodman (1978) reported a number of possible parental reactions to a child with a diagnosis of a developmental disability. Goodman (1978) stated one theory proposed mothers go through six stages in response to learning of a disability. These stages are similar to the Kubler-Ross theory of grief and loss. However, Goodman's theory is more specific to the reaction of mothers upon learning of a diagnosis of a disability. Goodman reported the stages are: 1) awareness, 2) denial, 3) recognition, 4) search for a cause, 5) search for a cure, and 6) acceptance.

Goodman also reported mothers went through a series of crisis: 1) novelty shock, 2) value crisis, and 3) reality crisis.

Although many of the stages are similar, the mothers seem to carry a feeling of life long grief. The mothers may go through stages, but it seems the levels may not be concurrent. The mothers may go through a stage, only to experience a crisis, and revert back to a past stage. Goodman (1978) stated the grief of a mother is lifelong and the mothers may feel guilt and anger frequently throughout their lives. Therefore, regardless of the stages, the sorrow felt by mothers may lessen at times, but continues to remain constant throughout the life of the child and the mother.

The question which the research pursued is how does an adult child with a developmental disability impact the mothers? The study investigated the process mothers endured in the journey

of having an adult child with a disability. Areas discussed with mothers of adult children with disabilities were how the mothers have adapted to having an adult child with developmental disabilities. In addition, the research also evaluated how the mothers perceived how the immediate and extended family and community reacted to their child. In addition, the research also discussed how the mothers dealt with issues concerning their child living outside of the home, and having an adult child with a disability has affected and changed their lives. The purpose and significance of the study is due to a lack of information and research on mothers with adult children with developmental disabilities. As the general population ages and lives longer, there is a greater need for services for the elderly and individuals with disabilities. In addition, due to medical technology, individuals with disabilities are also living longer. Therefore, the mothers and the adult children with disabilities are both living longer and each population may need more assistance with activities of daily living as they grow older. However, the research indicates the mothers of adult children with developmental disabilities are hesitant to lose full custody of their adult child, even when the mother is unable to care for herself or her child adequately (Seltzer, 1992). Thus, the need for the research exists to allow a better understanding of how the mothers perceive the impact their child with a disability has had on their life. In addition, the service providers need to be aware of the hopes and fears the mothers have regarding their child to best serve the family and the adult child with the disability.

CHAPTER III:

Methodology

This section described and explained the research question, design, and instrumentation used in the study. It also describes the sampling, variables, procedures and data analysis of this study.

Research Question and Design

The question which the research pursued is how does an adult child with a developmental disability impact the mothers? The study investigated the process mothers endure in the journey of having an adult child with a disability. Areas discussed with mothers of adult children with disabilities were how the mothers perceived how the immediate, extended family and community reacted to their child. Also discussed in the study were placement issues, and how having an adult child with a disability had affected and changed the lives of the mothers.

The research design was a qualitative, exploratory and descriptive design which employed a semi-structured interview guide.

Characteristics of the Sample Population

The sample was selected through snowball sample. Mothers were chosen to be participants in the study due to a lack of response from fathers with adult children with developmental disabilities and several fathers declined to participate in the study with the mothers.

There were 3 criteria for participation in the study. The criteria for participation in the study was 1) a mother of an adult child, 2) mother must be 45 years of age or older and 3) the adult child had to be age 22 or older, with a developmental disability. The adult child was required to have an standardized IQ of less than 70 points. A developmental disability, is conceptualized as autism, physical and sensory delays, and communication disorders. The term

“developmental disabilities is defined by the Developmental Disabilities Act of 1994 (P.L. 103-230) as: ...a severe, chronic disability of an individual 5 years of age or older which:

1. Is attributable to a mental or physical impairment or combination of mental and physical impairments
2. Is manifested prior to the age of 22
3. Is likely to continue indefinitely
4. Results in substantial functional limitations
5. Reflects the individuals need for a combination and sequence of special, interdisciplinary, or generic services (Minnesota Governor’s Council on Developmental Disabilities, 1995)

Subject Recruitment

An advocate from Arc and a county social worker were contacted by the researcher and were requested to speak to mothers of adult children with developmental disabilities. A social worker from an out-state county was also contacted. The social worker specialized in serving adults with developmental disabilities and offers services such as case management, information and referral, advocacy, day treatment and habitation and residential services to individuals who qualify for services.

The advocate and social worker were informed of the study and possible benefits and risks. The researcher requested that if the mothers were interested in participation of the study, to contact the researcher for more information. The mothers were then given the researcher’s phone number without pressure from the advocates or the social worker regarding their participation in the study. The mothers contacted the researcher if they were interested in participating in the study.

Research Terminology

Mothers: This was operationalized as any woman who had a child biologically or had adopted a child.

Adult child with a developmental disability: This was operationalized as any individual over the age of 22 who meets the criteria as having a developmental disability set by the Governor's Council on Developmental Disabilities, described previously.

Home of origin: Operationalized as the parental home where the adult child may continue to live or has moved from into another home.

Adult Foster Care: This was operationalized as to how The Minnesota Department of Human Services defines foster care as "licensed foster care provided by a family or a single person who provides care and supervision in their homes; or by a corporation that sets up a home and hires staff to provide the supported living services" (November, 2000). The adult foster care providers may be either corporate or private, family foster care. The corporate foster care model consisted of three to four individuals with developmental disabilities living in a house in a community setting. The corporate foster care model is staffed with "shift staff", trained employees providing assistance and supervision to the adults with developmental disabilities in the foster home around the clock. In the corporate model, there are typically a number of individuals who are employed in the home. Whereas the family foster care model consisted of four or less individuals with developmental disabilities living in a private home of a foster care provider. In the family foster care model, the individuals with developmental disabilities may live with a couple and their children. The couple or "parents" provide the assistance and supervision to the adults with disabilities.

Instrument Development

The interview guide was developed through a comprehensive review of the literature, extensive discussion with social workers and personal clinical experience in working with families with adult children with developmental disabilities. The interview guide consisted of 45 questions with items grouped into six categories:

1. Reaction of immediate family to the adult child

Example: How has the diagnosis affected you and your family overall?

2. Activities of daily living

Example: How much assistance does your child need with dressing?

3. Community involvement

Example: What involvement have you and your child had in community organizations?

4. Ability to work outside the home

Example: Has your child been able to work outside the home?

5. Reaction to learning the child had a disability

Example: What were your first thoughts and feelings when you learned your child had a diagnosis of a developmental disability?

6. Placement issues

Example: What are the main reasons for keeping your child at home or allowing them to live outside the home?

Data Gathering

The research study was one interview with each of the subjects. The study included 5 participants. The interview questions are attached as appendix D. All statements by the participants were transcribed and documented for review by the researcher. The researcher compiled all of the information, assessed and reported the findings of the significant impacts which the mothers reported.

The mothers were asked open-ended questions by the researcher, designed to determine how the mothers were impacted by their adult child with a developmental disability. How the mothers are impacted was conceptualized by discussing if the mothers had a physical, emotional and spiritual reaction to learning their child had a developmental disability. In addition, the impact was conceptualized as to how the mothers reacted to futures planning for the adult child.

How the mothers were impacted was operationalized as how the mothers coped with having a child with a developmental disability. In addition, impact was assessed operationally as to how the lives of the mothers was different with an adult child with a developmental disability rather than a child with an IQ above 70. The purpose of the scoring of functioning level of the adult child was to determine if the adult child had greater physical needs and a higher degree of developmental disability and if those needs had an impact upon the mothers. Impact was both positive and negative for the mothers as well as other family members. Any type of impact which the mothers indicated (sadness, anger, grief, joy) was considered as operationalized in the study.

Data Analysis

The responses obtained from each of the participants was carefully reviewed and analyzed. The information was compiled and evaluated to determine the nature and consistency of the impacts. Each of the participants responses to questions was considered for the study. Themes were developed from the similar and dissimilar responses of the participants. Each answer which correlated with one of the themes was considered as an significant impact on the mothers. Therefore, the responses were used as quotations in the study or in theme development. The purpose of the analysis was determined as to what type of impact the functioning and physical capabilities of the adult child had on the mothers.

Reliability and Validity

Validity is defined by Rubin and Babbie (1997) as “a descriptive term used of a measure that accurately reflects the concept that is intended to measure” (G-9). Rubin, et.al (1997) go on to report validity requires four criteria for qualitative research. 1) The research should be consistent with the rest of the research, 2) all of the research should be considered, 3) the theme should be the most dominant of all the research completed and 4) the theme or findings should be significant. Therefore, as the all of the mothers responses were consistent with the other participants, all of the research obtained was considered, the theme of an adult child with a developmental disability does have an impact upon the mothers was the most dominant. Finally, the themes and findings were significant. Thus, as all four criteria were met in analyzing the findings for the study, the research conducted in this study should be considered valid.

Rubin and Babbie (1997) also defined reliability as the quality of measurement which would suggest that the same data would be collected each time in each research study. The reliability in this study should be high as the mothers who were interviewed were asked similar questions

throughout the interview and responded in the same manner each time.

However, as only five Caucasian women participated in the study, it would be difficult to determine validity and reliability across cultures or women who lived in the inner city. All of the mothers who were interviewed for this study, lived in rural or in the suburban areas of Minnesota. However, attempts were made to develop a sound methodology in consultation with advisors and colleagues.

Limitations of the Study

As stated earlier, the study has a limitations of a small, non-random, non-heterogeneous group. Due to the small sample size, the study cannot be generalized to a larger group. In addition, the study is not longitudinal. Therefore, the statements which were made by the participants were subject to how they were feeling on the day of the interview day. Thus, the validity may not be as strong as the responses may have changed if the date was different. In addition, the responses of the participants may have been erroneous, due to poor memories or the participants may have answered in the manner which they believed the interviewer wanted to hear.

CHAPTER IV: FINDINGS

Introduction of Findings:

All of the mothers who were interviewed described their adult children with developmental disabilities as having a significant impact upon their lives. All of the mothers had been offered the opportunity to give their child up for adoption or to a state institution at birth, but had refused the opportunity. Instead, the mothers all chose to take on the lifelong responsibility of caring for their child. None of the mothers regretted the decision, but reported they continued to physically care and attend to their child, far into adulthood. As one mother put it “she will always be home with us, and I will always take care of her” (Nancy).

Only two of the mothers continued to care for their adult children in the home of origin. The remaining mothers chose to allow their children to live outside of the home. However, the mothers continued to be active in their lives and involved in their care. The mothers all expressed concern for the welfare of their child following their death. The mothers were concerned about who would ensure the safety and well-being of their child, regardless of whether or not their adult child was living in the home of origin. All of the mothers anticipated a sibling of their adult child with developmental disabilities would resume the mothers caretaking duties after the mothers were unable to do so.

The mothers were able to describe in detail how their adult child has affected their lives. The researcher used quotations from the mothers throughout the findings to further emphasize the impacts. However, in order to protect the anonymity of the mothers and their families, pseudonyms were used.

The findings were separated into four themes. The first theme was related to initial reactions the mothers had when informed of their child’s developmental disability. The second

was how the mothers and their families adjusted to having a family member with a disability. The third dealt with out of home placement issues. Finally, the fourth issue discussed the mothers hopes and fears for their children as well as what they have found to be the most and least helpful experiences.

Demographics of Participants

The study consisted of 5 participants. All of the participants were women and all identified Caucasian as their ethnicity. Of the women, one mother identified herself as being between the ages of 40-49, three women reported they were between the ages of 50-59 and one woman reported her age as being over the age of 70 years.

All five women had been married. One woman was widowed at the time of the interview. Two women had been divorced, but later re-married. Four women reported they were married at the time of the interview.

The mothers reported the primary diagnosis of their adult children with disabilities. The adult children with disabilities consisted of four males and one female. Three of the men had a primary diagnosis of Down Syndrome. One of the men had a primary diagnosis of autism, with mental retardation. The woman had a primary diagnosis of severe mental retardation.

How Participants Answered the Research Questions:

Theme One: Initial Reactions to Diagnosis

How did you learn of your child's diagnosis of a developmental disability and what were your first thoughts and feelings when you learned your child had a developmental disability?

While learning about how the mothers reacted emotionally, it was important to find out where the mothers were when they learned of the diagnosis, the actual diagnosis, who told them of the diagnosis and in what manner they were informed of the disability. All of the mothers were in a hospital setting when they learned of the initial diagnosis, and were told by a doctor or psychologist. Two of the mothers had taken their children back to the doctor or hospital because they suspected that something was wrong in the development of their child. All of the children were under the age of five when they received their initial diagnosis of a developmental disability. The child who was the oldest to receive her diagnosis was two years when she was diagnosed with a developmental disability. Another child was a few months old when he was diagnosed with Down Syndrome. The other three mothers were told of the diagnosis immediately after the child was born.

Initial Reactions to Doctors

Four of the five mothers had very clear recollections of the setting where they were told, as well as the attitudes of the medical personnel who informed them of the disabilities. The fifth mother, could not recall the exact people or locations, but remembered the emotions of learning her child had Down Syndrome with tears when discussing the experience.

The four mothers who did recall the experience of being told their child had a developmental delay, had negative impressions of the doctors who delivered the news of their child. The mothers described the demeanors of the doctors as being cold or uncaring. One

mother stated “He came in and said I tell you your baby’s not normal. Just very blunt. He didn’t say Down Syndrome, he said he’s a mongoloid, that’s just an ugly word you know? The next day he came in and said he’s got this heart problem, the next day he came in and told me about this intestinal blockage. Finally, I said, what do you have against me?” (Beth).

Thoughts and Feelings

All of the mothers described their initial reactions upon learning their child had a developmental disability as being difficult. The primary response was concern for what type of life their child would be able to lead as they grew older. The mothers reported the doctors gave little hope for the children to ever live independently or develop any skills. One mother stated, “She told me point blank that he was Down Syndrome and he would never do anything but sit in a corner with a box and a couple of sticks or clothes pins. You know, that isn’t pretty. That took a long time to get used to.” (Carol).

The mothers all reacted to the news their child had a disability in a similar manner. All of the mothers expressed denial, anger, and sadness when discussing their adult child with a developmental disability. The mothers reported feelings of grief and loss upon learning of the disability. One mother stated:

I went through the typical range. There’s like 12 steps or like the 10 steps of grief. I cried. I’m a very emotional person, so I cry easily. The first was disbelief. I guess [I thought] it was wrong and then I mourned. I was very unhappy. We knew there was something wrong when he was first born. He didn’t cry, he was listless, he didn’t have the reflex to nurse (Joyce).

Recommendations for Institutionalization

All of the mothers reported being given the option to place their child in an institution by the doctors or hospital. The mothers reported two of the fathers were open to the idea of placing their child into a facility for children with developmental disabilities. Both of the mothers chose not to place their child outside of the home. However, the two fathers who suggested placing the child outside of the home, eventually were divorced from the mothers and had little contact with the child with disabilities. All of the mothers were the primary caregivers for their child with disabilities. One mother stated:

When he was first born, my ex-husband said its your choice, you can either keep him or give him up and I said its not a choice. I would always wonder if I couldn't have taken him and stuff. My spouse couldn't handle him at all, just very little or nothing to do with him at all. I don't think he ever even held him. He wouldn't watch him so that I could go shopping. If I went anyplace the kids came with me. He just didn't want any part of anything financially, or never helped financially or in any other ways. And then he left and we were divorced a couple of years later (Beth).

Search for a cure

In addition, the mothers also questioned the causes of the disability which afflicted their child. Two of the mothers reported seeking solutions or cures for their child's disability. In addition, two of the mothers wondered if their child's disability was their fault or due to a genetic trait. The mothers seemed to want to assure themselves. One mother stated: "We went around, I was concerned it was a genetic thing. I went around to geneticists, I had him tested along the years. They did several chromosome analysis, everything checks out fine" (Joyce). One of the

mothers did seek treatment for her son from a specialist in another state. Her family traveled several times to visit the out-of-state doctor and spent their own money on treatments to improve his condition. The mother did feel that their son improved following the use of the nutritional supplements. The mother explained what they had done for their son.

We prayed a lot and we found a doctor. I get the Prevention magazine. I read through it and there are letters in there of people asking questions and telling things. There was this letter from this lady who said we have this Down Syndrome child and we found this doctor in Michigan and he has been going to him and its just amazing what he has done, and he makes his own medications for these children We went to this doctor and in the meantime, Jon was in school. This doctor said, now don't tell anyone that he's taking this medication, just go ahead and give it to him. They were taking these state tests. His teacher called and she was so excited she just couldn't believe how well Jon had done, and so then I told her about this medication that he was on. It was a big thing, we think. If we'd found out about it sooner, why, he would probably have been...(Carol).

Spiritual Reactions

All three of the mothers with children with Down Syndrome reported their places of worship were supportive to themselves and their adult child with the disability. One mother reported she developed a Sunday School program for her autistic son. However, one mother stated that the church community was not supportive of her daughter, due to her disability. The mother expressed anger towards the church for not accepting her daughter into the church community. She stated:

The Lutheran church has a lot of elderly people, so she was kicked out of her vacation bible school class. So, her sister took her into her class. We actually left that church, so we went to the Methodist church, because somebody told us they were very good for disabled people. So, we changed religions, went to the Methodist church. They wouldn't let her go in for the children's service. They would complain about her, so I was very angry, so we left that church about that time (Nancy).

Four of the five mothers reported their spirituality became an important part of their life when they discovered their child had a disability. All of the mothers reported they were active in the Christian faith and beliefs. They stated that their spirituality was strengthened following their child's diagnosis. Although they stated they did not blame God for their child's disability, they did ask why their child and why it had to be them. None of the mothers expressed anger towards God. One mother stated that her first thought when she learned her son had Down Syndrome was that God was punishing her for something she had done when she was younger. She went on to express her belief in this manner:

Someone told me that, that God was a God of love, he wouldn't give me this child with these kind of limitations if it wasn't for some kind of punishment. So, I dealt with that for a while, and then I said, no, he was a gift. He was a gift. I looked at these kids and said he's such a special baby, that God gave him to me for a reason, to teach us that everyone is not just perfect, he teaches you. Kevin has taught people so much about love, they don't know, what hate is, kids are taught not to like this, he never did that, he loves everybody and is a good guy (Beth).

Sense of Pride

However, despite the feelings of grief, all of the mothers reported being very proud of their child and of their accomplishments. Four of the mothers were proud of their child's abilities to socialize with others. They also expressed pride in their good manners. The mother also stated how much other people enjoyed being around their child and the relationships which their child has developed. As one mother put it, "he is a very lovable kid (Beth)."

The fifth mother reported being proud of her son's work ethic. She stated that her son has worked very hard in his job as well as in achieving each milestone in his life. She explained her feelings in these words:

Of the 3 kids, he is the one who has worked the hardest. I am so proud of that kid. Joshua has a Ph.D. in math, is teaching at Stanford, and I believe that Kyle has worked harder than Joshua. Kyle has a lot of barriers to overcome, an awful lot, and Joshua didn't have those barriers (Joyce).

Summary

Out of all the themes discussed, the issues revealed in the above section were most likely the most painful for the mothers. The mothers were very graphic and emotional about their responses to the questions of how they reacted when they initially learned of their child's developmental delays. All were very strong in their determination to care for their child, despite the obstacles they faced. In addition, all of the mothers displayed a strong attachment to their adult child and expressed a great deal of pride in their accomplishments.

Theme Two: Impact on the Family:

How has the diagnosis of your adult child affected you and your family overall?

This study sought responses on how the adult child's developmental disability has impacted the family, the relationship between the mother and her spouse and finally, how the mother feels having an adult child with a developmental disability has impacted her life.

Family

All of the mothers expressed pride in their child with the disability. In addition, pride was also expressed in their other children for supporting their sibling with the disability. They also reported that they felt that their family was very close. One mother stated "I think it has made us closer. I really do" (Carol). However, two of the mothers did report that they were limited as to the family activities due to their child with a developmental disability. The mothers stated that due to the precarious health of their child, they were unable to take family vacations or leave their child alone for any length of time. One mother reported "It limits you to what you do. We probably didn't go out as much as we could have at first, trying to find the appropriate person to come and babysit" (Pam).

Relationship between Mother and Spouse

Three of the mothers did not feel that their relationship changed between themselves and their spouse when they learned their child had a disability. However, all three mothers reported that they were grateful to have their husband's support throughout their experiences. They stated they relied a great deal on their husbands for seeking services for their child. One mother expressed her feelings in this manner: "I'm glad we had each other. It was just something that we went through together. We went through other things together that were far worse" (Joyce).

The other two mothers felt that the relationship between themselves and their spouses was

strained due to the challenges a child with a developmental disability may cause. The mothers reported their already tenuous relationships with their husbands became even more strained after they learned of their child's disability. The two mothers both felt they carried a majority of the responsibility for the care of their children, and became resentful of the fathers of their children. One mother reported the father chose not to be involved in the life of his Down Syndrome son. Another mother stated the father of her daughter simply chose not to become involved in his daughter's programming decisions. Thus, the mothers became resentful of the lack of involvement on the part of the fathers. One mother explained how her daughters disability impacted the marriage in this way:

I was very resentful. He wasn't carrying as much as he should have been, the load. I was resentful that he didn't come to meetings, learn these things for himself. This was so new to me, and trying to explain to him what I had heard and what's going to be done. I just gave up after a while, I didn't even try with that marriage. It maybe brought it to a head, more quicker, it was after she was placed that we finally separated and got divorced. He didn't want to. Yeah that had an impact on it, but who's to say what had more impact, the fact that you had to sell your house, move into an apartment, your children had to change schools, it was all of this (Nancy).

Mothers Adjustment

All of the mothers reported that they feel that they had adjusted well to having an adult child with a developmental disability. However, the 3 mothers with Down Syndrome children adjusted more quickly than the mothers whose children had autism or autistic tendencies. The 3 mothers reported that they felt that they themselves, as well as their family has adjusted and

adapted well to having an adult child with a developmental disability in the family.

The other two mothers reported they adjusted through dealing with the social service system for their children. They indicated they have adjusted well, but it was a long process over many years to adjust to their child's disabilities. One of the mothers explained, she asked how she had adapted to her daughter's disability, "I think pretty well, except when I remember back to how devastated I was to find this out. It's more of a slow, not devastation, but a real concern for what happens after I'm gone" (Nancy).

In addition, both mothers began working in the social service field to assist other families in similar situations. Both mothers felt they were able to use their influence and knowledge about the social service system to assist their own children as well as other consumers of the system. One mother stated when asked how she adjusted to her child's developmental disability "I am working here, in the field, helping other families who need help" (Joyce).

Summary

The above finding sought answers to questions regarding adaptation for the mothers and their families. Overall, the mothers reported they had adapted very well, especially the mothers who children had a diagnosis of Down Syndrome. The mothers also reported that they felt the adversity they had faced with their child having a disability had made the family stronger. The mothers who had strong marriages and relationships prior to learning their child had a developmental disability, felt their relationship with their spouse was stronger because of the challenges they faced with their child. However, the mothers whose relationships with their spouses was more tenuous, reported more difficulties in their relationships.

Theme Three: Out of Home Placement Issues:

What are the main reasons in choosing to keep your adult child at home or to allow them to live outside the home?

The interview guide asked the mothers if their child had lived outside of the home in the past and how they felt about the experiences. Questions which were also asked, what were the main reasons for keeping the children at home or for allowing them to live outside of the home?

The interview guide also asked the mothers the primary reasons for choosing to continue to keep their child at home or for allowing their child to live outside of the home. In addition, the mothers were also asked why the adult children lived at home as long as they did.

Past Experiences

The three mothers who did choose to allow their children to live outside of the home, all reported very poor experiences with the service providers. One of the mothers allowed her daughter to live outside of the home at the age of eight, because she felt that she could not longer provide quality care for her daughter. However, she reported dissatisfaction with the first two service providers until a family foster home was found for her daughter. The other two mothers also reported being unhappy with the service providers or adult foster homes. The reasons for the dissatisfaction were varied but one mother reported her displeasure with the adult foster care providers in this manner:

Staff turnover is high. Staff quality is downright disgusting, low, bottom low.

Unemployment here is so low, the unemployment rate that you only get people who really are not educated in the field. At least not educated in the way they should be educated. They may go through a week orientation, but that's not education. My husband now wants him to move out of this one, but I don't

know, because the services, and I think he's going to get the services no matter where he looks now a days, because it ain't there (Joyce).

Main Reasons to keep in the Home of Origin

The research which was conducted, found three of the five mothers interviewed had chosen to allow their children to live outside of the home of origin. The two adult children who continued to live at home both had Down Syndrome, were both males, and were in their early twenties. Both of the individuals who continued to live at home had significant medical conditions, and their mothers cited concern for their health as a reason for continuing to keep them in the home of origin. The mothers were concerned that if their sons moved outside of the home into adult foster care, their medical needs would not be recognized and treated. One mother explained the main reason for keeping her son at home was:

Probably because of his health, now is the biggest reason. I thought, if you put him in a group home, who knows how much attention he is going to get? Would he just be sitting in a corner, vegging out? Forget it, I don't want anything to do with anything like that. Now with his health, too. Its easier for me, I'm used to what's wrong with him and when I need to get him to a doctor and that kind of thing. I couldn't let somebody else take care of him (Pam).

Main Reasons to Live Outside the Home of Origin

The primary reasons two of the mothers allowed their children to live outside of the home was because they felt they were unable to provide adequate care for their children. One of the mothers placed her eight year old daughter into a facility for developmentally disabled and mentally ill children. The other mother became physically ill and was not longer able to care for her son without assistance. The third mother, chose to allow her son to live outside of the home

after encouragement and pressure from her children. She reported the children were concerned that she and her husband would not be able to care for their son as they were getting older and becoming more physically frail themselves. All three reported being very sad when their child moved to live outside of the home. However, they felt that their child would receive better care outside of the home and increase the independence due to the foster home providing more activities and interaction for their adult children. One mother discussed how she determined her daughter needed to be placed outside of the home:

I would have kept her home, had I been able to physically with her tantruming, which was still so bad. I couldn't let her go, she was my baby and I wanted to protect her. She wasn't being educated. She just wasn't. She was going to a program. Her behaviors had gotten so out of control. They couldn't educate her. It was that and my mother saying to me, you are not helping her, you are doing more to harm her than helping her. Boy, it was hard to let go. I knew there was nothing I could do to help her. All that we were doing was catching things that she was throwing in the air. It was horrible. And then you couldn't go anywhere and it was getting more and more difficult to find a baby-sitter. She was becoming very uncontrollable (Nancy).

Summary

The section on out of home placement was also a very painful topic for the mothers. All of the mothers reported wanting to care for their children in their own home or home of origin. However, the three who chose to allow their children to live outside of the home all felt that their adult children would receive gain more independence and be able to participate in more community activities in an adult foster home.

Theme Four: Hopes and Fears for the Adult Children

What are your hopes and fears for your adult child?

What has been the least helpful and what has been the most helpful in your experiences?

The final section in the interview guide asked the mothers about their hopes and fears for their adult children with developmental disabilities. In addition, the mothers were also asked what they have found to be the most and least helpful in their experiences in raising a child with a developmental disability. The mothers were allowed to define and choose their hopes and fears as well as what they found to be the most and least helpful experiences.

Hopes

All of the mothers indicated their hopes were to have their adult child be as independent and happy as possible in life. They wanted to see their adult child become more independent while living in adult foster care, in the community. In addition, the mothers also expressed hope that their child would find happiness in life. One mother explained: “[My hope is] that she will be happy. To be happy as often as she’s happy, that that would continue” (Nancy).

Fears

Similarly, the mothers all also expressed fears in what will happen to their child when they are gone. They all acknowledged the support systems their adult child has available to them, such as family, and government social services, but were afraid that their child would not have as much family contact when the mothers die. The mothers recognized that their other children have lives of their own, and may not be able to spend as much time with their adult child with the developmental disability as the mothers are able to spend now. One mother stated: “I know she wouldn’t have as much family contact when I’m gone. Her sister would always see her, but it probably wouldn’t be once a month. Not because she wouldn’t want to, but because of how her

own life evolves” (Nancy).

In addition, the mothers were also afraid that their adult child would not receive quality care from the service providers after they have died. The mothers expressed concern their children will not receive as much attention or quality care when they are not there to ensure the providers fulfill the wishes of the mothers. One mother expressed her fears in this manner:

My fear is what’s going to happen after I’m gone. I’m here now and I can be on top of them and challenge them and everything else. Get goals written down and be sure they stick to the goals. What’s going to happen when I’m not here? His brother and sister are not here. My sister may not be around, she’s my age, we’re twins. The system may devour him (Joyce).

Experiences Which Mothers Found Least Helpful

All of the mothers were able to identify experiences which they did not feel were helpful. The responses to this question were quite varied. One of the mothers felt that her inability to rely on her husband for assistance with her son was the least helpful. Another mother felt the lack of funds available to individuals and their families with disabilities was the least helpful. Yet another mother felt that the schools and the lack of preparation for the workforce was the least helpful in her experiences. However, two of the mothers found that the medical profession was the least helpful. Each of these mothers had boys with Down Syndrome. Both of these children had significant health concerns throughout their lives. Therefore, the mothers felt the doctors did not give enough information or options for their adult children. One mother explained her frustration by stating “I think that when the hospital tells you this is the way it is, then at least give you some resources to work with” (Pam).

Experiences Which Mothers Found Most Helpful

All five of the mothers identified experiences which they found to be helpful. The responses to this question were similar. The two mothers with the boys with Down Syndrome felt that the school district was the most helpful for their children. They explained that their children got along with others well while in school. In addition, they felt the school “has some very special people” (Beth). The mothers also responded that they felt other people, such as family members, church members and neighbors were very helpful in their experiences with their adult child.

Two of the mothers corroborated in what they believed that no one outside was able to help them as they coped in finding and improving services for their child with developmental disabilities. Instead, they felt that their own abilities to find services and assistance for their child was their most valuable asset. It should be interesting to note both of these mothers had adult children with autistic tendencies. One of the mothers expressed her feelings when asked what was the most helpful to her in this way:

My stamina. Isn't that sad? I don't think anyone from outside has helped me most, my kids, my husband, and my stamina. Not a person. There were well intentioned people but they were not knowledgeable, and I wasn't going to start educating them. (Sighs) I burned out, I did, I burned out (Joyce).

Summary

The hopes and fears which were discussed in this section displays many mothers have similar feelings in regards to their children, regardless of any disability. All of the mothers wanted their children to lead happy, and healthy lives, which would be as normal as possible. However, these mothers are aware that their children with developmental disabilities will never lead completely “normal” lives. However, the mothers continue to hope for the best for their

adult children. The mothers also agreed that their best resources were their families and friends, and their own abilities to survive throughout the challenges they face with their adult child.

CHAPTER V: DISCUSSION AND IMPLICATIONS

Introduction:

In this study, five women discussed their feelings and experiences in raising an adult child with developmental disabilities. All five women displayed emotion, passion and determination in dealing with the community, the government and social service providers as they sought the best possible lives for their children. Above all the strengths and assets the women found in their battles to secure better lives for their children, each woman's greatest asset was herself. Due to the small study sample, it would be difficult to generalize this study with all mothers with adult children with developmental disabilities. However, a great deal can be learned from this study and its participants.

This chapter reviews the findings from the interviews and the overall themes. In addition, implications for practice, policy and future research will also be discussed.

Impact

The study results indicated all of the mothers were greatly impacted by their adult child with developmental disabilities. The passion and pride which the mothers in this study displayed for their adult children with developmental disabilities was tremendous. The mothers recognized from the beginning that they had the ultimate responsibility to care for and advocate for their children with disabilities. All of the mothers displayed a great deal of emotion when discussing their children. Regardless of the topic questions, the mothers showed devotion and protection towards their adult child. The positive emotions which the mothers portrayed were more significant than the negative impacts.

However, as anticipated, the mothers with Down Syndrome children did appear to be more satisfied with life and accepting of their child's disability. The information which the mothers with

Down Syndrome reported was consistent with a study conducted by Seltzer et al (1993) which found mothers with children with Down Syndrome seemed to be more optimistic, satisfied with life and were more accepting of their child's disability. The other two mothers expressed frustration with the community for not understanding their child's limitations and disability. In addition, the mothers of the Down Syndrome children reported being very proud their child was so well liked by their teachers, peers, friends and neighbors. The mothers of the other two children did not report strong relationships with similar networks. Thus, the research was consistent with the findings of this study. Seltzer, et al., (1993) reported when an adult child has Down Syndrome, there are fewer negative outcomes for the family, than when the developmental disability is related to other issues.

Stress and Personal Burden

The research had indicated the mothers of adult children with developmental disabilities had a great deal of stress and personal burden due to the amount of responsibility required by the adult children with disabilities (Hayden & Goldman, 1996). The research primarily discussed the perceived issues surrounding lack of planning and support for families with an adult child with a developmental disability. The mothers did express a great deal of stress when they discussed difficulty in finding what they felt were appropriate homes for their adult children. However, the mothers did not cite a lack of support or resources in their experiences. In fact, all of the mothers reported the social service system and social workers had been very supportive for themselves and their adult children.

However, the research did not indicate the pride, dignity and perseverance which these mothers displayed. The mothers who were interviewed for this study exhibited a great deal of strength and determination. All of the mothers had learned to advocate for their children as well

as learn how to use the social service system to obtain necessary services for their child with disabilities. Krauss et al., (1993) also found women with adult children with developmental disabilities felt like pioneers in the field of disabilities. They felt that they were able to create new opportunities for their children and were proud of their accomplishments.

In addition, all of the mothers reported learning a great deal from their child with disabilities. In fact, one of the mothers reported she had benefited and learned more about life from her son with disabilities. She expressed her beliefs in this manner:

When I was married, I was very quite, unassertive, afraid to do things and I had Kyle. Because I had to learn to be assertive, to read the law, and to interpret it. I had to learn all of that. It was a new me that was arising. I did that and my self-esteem went up, I was coming into my own. If it hadn't been for Kyle, he helped me as much as I helped him. It wasn't a one way street (Joyce).

Future Planning

The research depicts the mothers of adults with developmental disabilities, as often not being knowledgeable about the system or planning for the future. However, this study demonstrated that mothers with adult children with developmental disabilities are very aware of the issues and are able to assist their children in planning for the future. Four of the mothers had done a great deal of planning for the future, for their adult child, in the event the mothers were unable to continue to care for the child. In all five cases, the mothers anticipated family members would resume the care of their adult child, if they were unable to do so.

In addition, this writer began the study with the perception the mothers would be resistant to the idea of their adult child living outside of the home. However, this study found the opposite. Three of the five mothers had chosen to allow their children to live outside of the

home of origin. The mothers felt their adult children would increase their independence as well as participate in more community activities if they lived in adult foster care. In fact the mothers felt strongly that by keeping their adult child at home, they would be doing their adult child an injustice. The mothers felt their child would be able to learn a great deal more by living independently than to live at home. One mother put it this way:

Any child who lives at home past adulthood is doing themselves, the child is getting a disservice. That child will not learn to be independent living in the home. With mom and dad, I don't care how structured or how precise the goals are, the independence is not there with mom and dad around. I am a strong advocate of children moving out when they get to adulthood and becoming more independent because everyone can become more independent, no matter how severe the disability (Joyce).

Initial Reactions

The issue of how and when the mothers were told about their child's developmental disability seemed to have a significant impact upon the mothers throughout their lives. As stated earlier, the mother were able to recall, in graphic detail, as to how they were informed of their child's disability. Four of the five mothers stated that they did not like the doctors who delivered the news. The fifth mother reported that the hospital did not give her any information regarding her son's disability. Thus, all five mothers reported dissatisfaction with how the doctors and hospitals handled the sensitive topic of informing the mothers their child had a developmental disability.

The literature review which was completed for this study did not find information which discussed the implications of how parents were informed their child had a developmental

disability. However, out of all the questions which were asked, how the mothers were informed their child was disabled remains the most prominent. The mothers were very specific as to their frustrations with the medical profession as to how they were informed. The question is raised as to whether or not the mothers would have been frustrated with how they were told, regardless of how tactful and gentle the doctors attempted to inform the mothers. In addition, the doctors or other individuals who may have observed the process may have a different viewpoint of how the mothers were informed. However, regardless of the viewpoints, the mothers were clear that serious consideration needs to be taken by the doctors as to the best way to inform parents their child has a developmental disability.

Policy Implications

In the past five years, mothers of individuals with developmental disabilities have advocated for increased services for their children. The governmental services have increased for individuals with disabilities. However, the medical and health insurance services which are available are tightly restricted and very regulated. The mothers, as well as the individuals with disabilities are required to provide a great deal of documentation in order to receive health insurance or Medicaid. This researcher would recommend universal health care coverage for all individuals, not just individuals with disabilities. Thus, eliminating the need for mothers to provide the government documentation and verification a disability exists in order to obtain Medicaid insurance coverage for their adult child.

Practice Implications

The implications for this study for social services as well as for the medical profession would be to first and foremost, seriously consider and contemplate the ramifications of how the parents and families are informed their child has a developmental disability. A great deal of

caution needs to be taken in this matter, as it will affect the family for the rest of their lives. In addition, information and support needs to be available for the parents following the diagnosis. It may be helpful if other parents of children with similar disabilities contacted the parents at a later date to provide support and additional information.

In addition, the social service field needs to focus on the strengths of families who have an adult child with a developmental disability. All of the mothers interviewed displayed a great deal of pride and strength. The mothers were aware of the services available to them and were able to advocate for themselves. Therefore, individuals in the social service, medical and educational fields need to educate families on the services available. In addition, the professionals need to focus on what the adult child with developmental disabilities is able to do, instead of their limitations. The parents need to hear that they can love and be proud of their child, regardless of the disability. One mother expressed her feelings this way:

I don't lament the fact, most of the time, 99.9% of the time, there are times when I do. I am human. I don't lament the fact that Kyle is not "normal" He is what he is. I rejoice in each milestone. It does no good to lament the things that the child can't do, you should focus on the things the kid can do (Joyce).

Finally, this study has shown mothers with adult children with developmental disabilities have a great deal of strength and integrity. It has also shown that these mothers are not that different from any other mother. They fear what will happen to the child after they have gone, they fear rejection for their child, but most of all, they want their child to be happy. Perhaps the only difference is how society perceives their children.

References:

Engelhardt, J.L., Brubaker, T.H., & Lutzer, V.D. (1988). Older caregivers of adults with mental retardation: Service utilization: Mental Retardation, *26*, 191-195.

Fishley, P. (1992). I am John. Health and Social Work, *17*(2), 151-157.

Fullmer, E.M., Tobin, S.S., & Smith, G.C. (1997). The effects of offspring gender on older mothers caring for their sons and daughters with mental retardation: Gerontologist, *37*, 795-803.

Goodman, D. M. (1978). Parenting an adult mentally retarded offspring. Smith College: Studies in Social Work, *XLVIII*(3), 209-234.

Greenberg, J.S., Seltzer, M.M., Krauss, M.W. & Kim, H. (1997). The differential effects of social supports on the psychological well being of aging mothers of adults with mental illness or mental retardation. Family Relations, *46*, 383-394.

Griffiths, D. L. & Unger, D.G. (1994). Views about planning for the future among parents and siblings of adults with mental retardation. Family Relations, *43*, 221-227.

Haveman, M., van Berkum, G., Reijnders, R., & Heller, T. (1997). Differences in service needs, time demands, and caregiving burden among parents of persons with mental retardation across the life cycle. Family Relations, *46*, 417-425.

Hayden, M.F. & Goldman, J. (1996). Families of adults with mental retardation: Stress levels and need for services. Social Work, *41*, 657-668.

Heller, T. (1993). Self-efficacy coping, active involvement and caregiver well-being throughout the life course among families of persons with mental retardation. In A. Turnbull, J. Patterson, S. Behr, D. Murphy, J. Marquis, & M. Blue-Banning (Eds.), Cognitive coping, Families and disability (pp. 173-182). Baltimore: Paul H. Brookes.

Heller, T., & Factor, A.R. (1993). Support Systems, well-being, and placement decision making among older parents and their adult children with developmental disabilities. In E. Sutton, A. Factor, B. Hawkins, T. Heller, G. Seltzer (Ed.), Older Adults with Developmental Disabilities: Optimizing choice and change (pp. 107-122). Baltimore, MD: Paul H. Brooks Publishing Company.

Heller, T., & Factor, A. (1988). Permanency planning among black and white family caregivers of older adults with mental retardation. Mental Retardation, *26*, 203-208.

Heller, T., Factor, A., Sterns, H., & Sutton, E. (1996). Impact of person-centered later life planning training program for older adults with mental retardation. The Journal of Rehabilitation, 62, 77-84.

Heller, T., Hsieh, K., & Rowitz, L. (1997). Maternal and paternal caregiving of persons with mental retardation across the lifespan. Family Relation, 46, 407-415.

Hollander, R. (1986). Mental retardation and American Society: The era of hope. Social Service Review, 60(3), 395-420.

Ineichen, B. (1986). A job for life? The service needs of mentally handicapped people living in the community and their families: British Journal of social work, 16, 311-323.

Krauss, M., & Seltzer, M.M. (1993). Coping strategies among older mothers of adults with retardation: A life-span developmental perspective. In A. Turnbull, J. Patterson, S. Behr, D. Murphy, J. Marquis, & M. Blue-Banning (Eds.), Cognitive coping, Families and disability (pp. 173-182). Baltimore: Paul H. Brookes.

Koch, R., MD & Koch, K.J. (1974). Understanding the mentally retarded child. New York: Random House.

Kropf, N.P. (1997). Older Parents of adults with developmental disabilities: Practice issues and service needs: Journal of Family Psychotherapy, 8, 37-54.

McDermott, S., Valentine, D, Anderson, D., Gallup, D. & Thompson, S. (1997). Parents of adults with mental retardation living in-home and out of home: Caregiving Burdens and gratification's: American Journal of Orthopsychiatry, 67, 323-329.

McCallion, P., Janicki, M., & Grant-Griffin, L. (1997). Exploring the Impact of Culture and Acculturation on Older Families Caregiving for Persons with Developmental Disabilities: Family Relations, 46, 347-357.

Minnesota Department of Human Services (2000). Waiver Services Program for Persons with Mental Retardation or Related Conditions [Brochure]. MN.

National Information Center for Children and Youth with Disabilities. (April 2000). Fact sheet: Learning disabilities definition., Retrieved from on-line database () on the World Wide Web: www.nichcy.org

Rubin, A., & Babbie, E. (1997). Research Methods for Social Work (3rd ed.). Pacific Grove: Brooks/Cole Publishing Company.

Scheerenberger, R.C. (1987) A History of Mental Retardation Baltimore, Maryland: Paul Brookes Publishing Co.

Seltzer, G.B., Begun, A., Magan, R., Luchterhand, C.M. (1993). Social supports and expectations of family involvement after out of home placement. In E. Sutton, A. Factor, B. Hawkins, T. Heller; G. Seltzer (Ed.), Older Adults with Developmental Disabilities - Optimizing choice and change (pp. 123-140). Baltimore: Paul H. Brooks publishing company.

Seltzer, M.M. (1992). Family caregiving across the full life span. In Louis Rowitz (Ed.), Mental retardation in the year 2000 (pp. 85-100). New York, New York: Springer-Verlag.

Seltzer, M.M. & Krauss, M.W. (1989). Aging parents with adult mentally retarded children: Family risk factors and sources of support. American Journal on Mental Retardation, *94*, 303-312.

Seltzer, M.M., Krauss, M.W. & Tsunematsu, N. (1993). Adults with Down syndrome and their aging mothers: Diagnostic group differences. American Journal on Mental Retardation, *97*, 496-508.

Seltzer, M.M., Greenberg, J.S., Krauss, M.W., Gordon, R.M., Judge, K. (1997). Siblings of adults with mental retardation or mental illness: Effects on lifestyle and psychological well-being. Family Relations, *46*, 395-405.

Ziolko, M.E. (1991). Counseling parents of children with disabilities: a review of the literature and implications for practice. The Journal of Rehabilitation, *57*, 29-34.

APPENDIX A:
COVER LETTER

ARC
Attention: Ms. Tori Jo Bates
1526 122nd Street
Burnsville, MN 55337

Dear Ms. Bates:

I am in the process of completing my graduate degree in Social Work at Augsburg College. One of my final projects is to write a thesis. I have chosen to focus on the aging parents of adult children with developmental disabilities. A part of my thesis project involves interviewing aging parents between the ages of 45 and above, who have adult children with developmental disabilities. I would appreciate the ability to place an ad in a newsletter which ARC sends out to individuals they serve. If the parents would agree to participate, the interview should take 60-90 minutes to complete. Their participation is voluntary. ARC's decision to allow the ad to be placed in the newsletter would not affect your relations with this researcher or Augsburg College. In addition, whether or not the parents chose to participate would also not impact their relations with ARC the researcher, or Augsburg College. All information obtained from the interviews will be confidential.

The purpose of this research project is to understand more fully what issues and obstacles significantly impact aging parents with adult children with disabilities. ARC's participation will help expand our knowledge in this area. I will gladly share the results upon request.

Thank you for taking the time to review my proposal. I hope that you will agree to participate. If you have any questions or concerns, please feel free to contact me at work at (651) 213-0341. Thank you for your assistance.

Sincerely,

Tracy J.E. Mitchell

APPENDIX B
CONSENT FORM

**HOW DOES AN ADULT CHILD WITH A DEVELOPMENTAL DISABILITY
AFFECT THE MOTHER?**

You are invited to be in a research study designed to evaluate how an adult child with a developmental disability affects the lives of their aging parents. Your participation is completely voluntary. I ask that you read this form and ask any questions you may have before agreeing to be in the study.

This study is being conducted by: Tracy Mitchell, in partial fulfillment of the Master of Social Work thesis requirement at Augsburg College.

BACKGROUND INFORMATION:

The purpose of the study is to understand how adult children with developmental disabilities impact the lives of their parents as the parents age.

WHAT WILL HAPPEN DURING THE STUDY?

If you agree to be in this study, I would ask you to do the following things. Participate in an audio taped interview which would last approximately 60-90 minutes. I am a master of social work student, working on my thesis and will be conducting the interview. You will be asked to discuss how having a child with a disability has affected your life, and the decisions you have made regarding the life of your adult child.

WHAT ARE THE RISKS?

It is possible during the interview, you may have painful memories and thoughts. If at any point during the interview, you feel too uncomfortable to continue, you may stop the interview without consequences. After the interview, the following 24 hour counseling referrals are available for you to contact, if the need should arise. However, any costs which are incurred if you chose to contact the counseling services would be your responsibility.

Hennepin County/Minneapolis Area	Crisis Intervention Center	(612) 347-3161
Seven County Metro Areas:	Crisis Connection	(612) 379-6363

ARE THERE ANY BENEFITS?

It is possible that you could experience an enhanced sense of well-being or satisfaction as a result of telling your story. Also participants will receive an honorarium, worth \$10.00 for their participation in the study.

CONFIDENTIALITY:

The records of this study will be kept private. In any sort of report, I might publish, I will not include any information that will make it possible to identify you. Research records will be kept in a locked file; only I will have access to the records.

The audio taped interviews will be transcribed by a trained transcriptionist and then destroyed.

The trained transcriptionist will be required to sign a confidentiality form to ensure your privacy.

Any identifying information from the interview, including your name, will be removed or altered on the written transcript. The transcripts will be shared with my thesis advisor during the process of writing the thesis. All information is confidential. However, I cannot guarantee anonymity due to the small sample size, but I will make every effort to maintain anonymity. Transcripts will be identified with numbered codes only and no names or identifiable information will be used in this study. Raw data, including the audiotapes, and notes will be destroyed no later than August 30, 2001.

VOLUNTARY NATURE OF THE STUDY:

You are free to withdraw from this study or refuse permission for the use of your interview or transcript at any time and the \$10.00 honorarium will be yours to keep. Your decision whether or not to participate will not affect your current or future relations with Augsburg College or with ARC. If you decide to participate, you are free to withdraw at any time without affecting those relationships.

Contacts and Questions:

The researcher conducting the study is Tracy Mitchell. You may ask any questions you have now. If you have questions later, you may contact me at (651) 213-0341. If I am unable to answer any of your questions to your satisfaction, you may also call my thesis advisor, Laura Boisen at (612) 330-1439.

You will be given a copy of the form to keep for your records.

STATEMENTS OF CONSENT:

I have read the above information or have had it read to me. I have received answers to questions asked. I consent to participate in the study.

Signature _____

Date _____

Signature _____

Date _____

Signature of investigator _____

Date _____

I consent to be audiotaped:

Signature _____

Date _____

Signature _____

Date _____

I consent to allow use of my direct quotations in the published thesis document.

Signature _____

Date _____

Signature _____

Date _____

APPENDIX C
DEMOGRAPHICS

Please answer these questions, so that we can provide documentation as to the types of people who participated in our study.

1. What is your gender?

_____ Male _____ Female

2. What is your marital status?

_____ Single (Never Married) _____ Married
_____ Divorced _____ Widowed

3. What is your age?

_____ 30-39 _____ 40-49
_____ 50-59 _____ 60-69
_____ 70 or over

4. What do you consider to be your ethnicity?

_____ Caucasian _____ African-American
_____ Asian _____ Hispanic
_____ American Indian
_____ Other (Please specify)

APPENDIX D
INTERVIEW QUESTIONS:
TO BE ASKED BY THE RESEARCHER:

1. How many people in your immediate family?

Genogram/ecomap

2. How do they react to your child?
3. What is the relationship between your child and their siblings?
4. How does your child feel about him or herself?

Now, I would like to ask some questions about your child's abilities:

5. How much general domestic activity does your child do independently
 - Washes dishes well
 - Makes bed
 - Helps with household chores
 - Can load and use dishwasher correctly

6. How much assistance does your child need with cleaning the house?

-Cleans living area

7. How much assistance does your child need with the laundry?

8. How much assistance does your child need with shopping?

9. Is your child able to prepare food independently?

-Can use microwave

-Mixes and cooks simple food (Mac and cheese, pancakes, hot dogs)

-Prepares simple foods requiring no mixing or cooking (cereal)

10. Is your child able to use the toilet independently?

11. How much help does your child need in bathing?

12. How much assistance does your child need with dressing?

COMMUNITY INVOLVEMENT:

13. What involvement have you and your child had in the community/organizations?

14. How does you feel the community has reacted to your child?

-School

-Church

-Extended family

15. How do you feel the community has reacted to your family?

-School

-Church

-Extended family

16. Has your child been able to work outside of the home?

Many times, one parent chooses to stay at home and take care of the children:

17. Did you and your spouse both work outside of the home?

18. How did you feel about working at home, or working outside of the home?

19. Did your child having a disability, impact your decision to work outside of the home or to work at home?

20. What diagnosis was your child given?

21. Where were you and your spouse when you found out about the diagnosis?

22. Who told you?

23. How were you told?

24. What were your first thoughts/feelings?

25. How did you and your spouse react:

-emotionally

-spiritually

26. Did you have a physical reaction shortly after you learned your child had a developmental disability?

27. How has the diagnosis affected you and your family overall?

28. How has the diagnosis of a disability affected the relationship between you and your spouse?

29. Who has supported you the most throughout your experiences?

30. How have you adjusted to having a child with a developmental disability?

31. How has your family adjusted?

32. What are you the most proud of in raising your child?

PLACEMENT ISSUES:

33. Has your child lived outside of the home in the past?

34. How did you feel about the experience?

35. What are the main reasons in choosing to keep your child at home or to allow them

to live outside of the home?

36. Do you feel the abilities of your child has impacted your decision or your ability to care for your child?
37. What has prevented you from your child moving outside of the home?
38. What are some of your hopes and fears in having your child live outside of the home?
39. What are your expectations for your family members to care for your child if you are unable to do so?
40. What are your expectations for the community to care for your child?
41. Looking back, is there anything you would have done differently?
42. What has been the least helpful?
43. What has helped you the most in your experiences?
44. What advice would you give to other parents with children with D.D.?

Augsburg College
Lindell Library
Minneapolis, MN 55454