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Expectations and Experiences of Fathers Who Have Parented Children
With and Without Intellectual Disabilities

A dissertation
presented to
the Faculty of the College of Nursing
East Tennessee State University

In partial fulfillment
of the requirements for the degree
Doctor of Philosophy in Nursing

by
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December 2012

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Keywords: Intellectual Disabilities, Fathers, Children,
Expectations, Experiences

ABSTRACT

Expectations and Experiences of Fathers Who Have Parented Children

With and Without Intellectual Disabilities

by

Jane K. Walker

The parenting experience is as diverse as the children parented. Each child has diverse personality traits requiring flexibility and specificity in parenting strategy. This need for flexibility and specificity is more complex when one or more children within a family has an intellectual disability. Although research in this area is abundant, investigators have historically focused on mothers' attitudes, beliefs, and behaviors to represent the entire family (Essex, Seltzer, & Krauss, 2001; Greenberg, 2002) rather than focusing on fathers and their caregiving relationships with their children in need of malleable but consistent parenting. Using a qualitative descriptive design, this qualitative study explored expectations and subsequent experiences of men who have fathered children with and without intellectual disabilities. The investigator collected data through face-to-face semistructured interviews with 8 fathers in Tennessee. During these interviews fathers discussed each of their children, specifically their expectations of and experiences with their children prior to birth, reactions to the differences among their children, getting through the day, and their responsibilities in teaching each child. NVivo 9.0 data management software was used. Four main themes were inductively derived from the data: *Learning to Dance in the Rain*, *Just Do What Needs Doing*, *The Power of Patience*, and *Nurturing Uniqueness*. These themes contribute to nursing knowledge by delineating the perspectives of men as they father children of differing intelligences. The results from this study suggest strategies for educators and practicing healthcare professionals working

with fathers in similar situations to increase mindfulness of this all-important relationship between fathers and their children with differing intellectual capacities; the investigator also proposes areas of continued research in this field.

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I pondered this question for months: How do I acknowledge those who have influenced my development as a nurse and an educator? My mother, Carolyn J. Wyss, never once said, "You should be a nurse!" and even kept silent as I chose a different path in the beginning. Well, Mom, I got it right on the second try! I guess I have a slight stubborn streak?

Although I didn't realize it while it was happening, I would not be the pediatric nurse I am today without the encouragement and expertise of Marty Rucker. I am honored as a "veteran nurse" to work with her, sharing the love of pediatric nursing to all students deemed worthy to care for these tiny gifts. Thank you is not enough for all you have done for me!

The dissertation process has been difficult to say the least! The one person who has been willing to fight the powers-that-be for and with me throughout its entirety has been Dr. Joy Wachs. We have both been through so much these past 4 years; it's a miracle we both hung in there. I am eternally grateful for that, your unending editing, and infinite encouragement through it all!

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DEDICATION

I would like to dedicate this research to the people who made it possible. First, my family-- my husband Rob and daughters Kellen and Kiryn. For those many times you guys wanted me to play or help and the answer was, "Just a minute, let me finish this thought" or "I can't go because I need to work on my paper", thank you for trying to understand and keeping the disappointment from showing on your faces. Rob, I know it's been a long haul with quite a roller coaster ride, but it's D-O-N-E.

Second, thanks are never enough for my mother Carolyn and step-father Kirk. For never doubting I could-- and eventually would-- finish the requirements for my doctoral degree, I can only hope I can be as great a cheerleader for my children as you both have been for me. Financially, emotionally, and all points in between, your sacrificial support is never ending.

To everyone who ever inquired as to its progress, whether a former or current student, colleague, family member, or friend, it's finally finished! Where should we go to celebrate?

I also dedicate this work to my heavenly Father without whom I am nothing. During all the times I thought I couldn't do it anymore, He carried me forward.

A special thank you to those fathers who trusted me to tell their stories of fatherhood. What beautiful pictures you painted of your children and families. I am forever in personal debt to you for helping me reach this goal and professional debt to you for allowing me to share your experiences. Finally, to all those families out there who expected "normal" perfection in their children and got something a little different but just as perfect, thank you for all you do to advocate for your children. Here's to you from both the maternal and paternal perspectives:

WELCOME TO HOLLAND

by
Emily Perl Kingsley

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this.....

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills....and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, *ever* go away... because the loss of that dream is a very very significant loss.

But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.

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DREAMS

by John Cox

While you spend a lifetime dreaming about your unborn child's potential accomplishments, it's generally not until the last few months before he or she is born that dreams go into high gear. You dream of the engineer, ballerina, or lawyer your child will grow up to be. And as the delivery date draws near, dreams gather momentum, fed by parents, friends, and co-workers until you half expect to see your child born 18 years old, highly educated and physically attractive -- perfect in every way.

It's humbling how dreams that build up over a lifetime can blow away like the air from a balloon. In the amount of time it takes for a doctor to say, "Oh no," dreams can turn to nightmares and hopes can turn to fears. All those long held dreams of perfection melt away into short term prayers and frantic thoughts of -- if only the baby will be all right.... what am I going to tell our parents?.... how did this happen?.... why us? In a matter of moments you have traded bar exams for brain scans, ballet shoes for blood tests, rock solid normality for ground breaking lunacy. I watched helplessly as my baby was poked and prodded by strangers who did not have the time to answer my questions or allay my fears.

Through it all I coped with a day-to-day roller coaster ride of good news, then bad, hopeful signs, then puzzling questions. I found myself unable to dream -- because I lived for the moment -- unable to see past the next doctor's visit or test, hoping that this time someone will be able to determine what is wrong or what will happen in the future. But I became more frustrated with each visit or test, as still more were needed, Worse yet, everyone finally said that only time would tell what the future would hold.

Slowly, very slowly, I realized that I would never know exactly what was going to happen until it did. At first I was angry -- I wanted answers -- but it dawned on me one day that I was really no different than any other father. No doctor or specialist can tell anyone of us how bright or physically capable our children are going to be. The most that we, and all parents, can hope for is that we make the best of what is given to us. This new realization liberated my wife and me. We began to look towards the future again, and we started doing things that would give us and our child choices.

I began to dream again. To be sure, these were not the same dreams as before, but as important. I dreamed of her first steps, and when they came, no parent was ever more proud of their child. My wife and I dreamed of including her in a regular education classroom at school, and after many battles, no parent was ever more emotional or proud when her first regular education teacher assured us that this is where she belonged. While receiving no straight "A" report card, the comments were cherished all the same.

I continue to dream of the future, of my daughter working, building meaningful relationships, and accomplishing great things for herself and others. I know that she will never be a lawyer, doctor, or ballerina -- but I dream all the same of what she can become -- and I cherish each step she takes along her way of accomplishments.

All children are a gift to their parents, grandparents, teachers - everyone that comes into contact with them. And they teach us all something that we would not have learned without them. For me it was to slow down so I could take pleasure in the details of my children's lives. I learned to take an active part in all my children's activities and to cherish each of their accomplishments. I couldn't have done it without her, and I am much richer for this experience. I would not wish it away.

I do remember wondering a few years back what my daughter would have been like if... I grieved for the loss of my "normal" life, somehow assuming that the one I had embarked on would not be as fulfilling. I don't think that way anymore. I am proud of my daughter's accomplishments, and like any father, I am looking forward to many more she will have as she matures. I need not have anguished about the future. Looking back, I see now that few others have been as blessed as I.

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CONTENTS

	Page
ABSTRACT	2
ACKNOWLEDGEMENTS	5
DEDICATION	6
WELCOME TO HOLLAND	7
DREAMS	8
Chapter	
1. BACKGROUND OF THE PROBLEM	16
Introduction	16
History of Intelligence Research: Pre-20th Century	17
Intellectual Disabilities: Changing Societal Norms	19
Pre-Colonial and 17th Century Beliefs	19
Eighteenth Century Familial Custodial Care to Societal Menace ..	20
Nineteenth Century Humanitarian to Isolation	21
Twentieth Century Eugenics to Enlightenment	23
Research Need and Purpose	33
Definitions	33
Significance to Nursing	36
Summary	37
2. LITERATURE REVIEW	39
Introduction	39
General Intelligence Research in the 20th and 21st Centuries	39

Geographic Metaphor	38
Computational Metaphor	41
Biological Metaphor	42
Epistemological Metaphor	44
Sociological Metaphor	44
Anthropological Metaphor	45
Systems Metaphor	45
Theoretical Foundations	51
Piaget's Theory of Cognitive Development	51
Role Theory	53
Functional Role Theory	54
Symbolic Interactionist Role Theory	54
Family Systems Theory	55
Chronic Sorrow	58
Current State of the Science	61
Mothers as Caregivers in Recent Literature	61
Siblings of Children with Intellectual Disabilities	64
Fathers as Caregivers and Their Expectations	67
Summary	72
3. RESEARCH METHODS	74
Introduction	74
Study Design	74
Population and Sample	74

Protection of Participants	77
Data Generation	78
Instrumentation	80
Field Notes	80
Reflective Journal	81
Interview Guiding Questions	82
Data Management	83
Rigor	83
Objectivity and Confirmability	84
Reliability or Dependability and Auditability	84
Internal Validity or Credibility and Authenticity	85
External Validity or Transferability and Fittingness	86
Applicability	86
Data Analysis	87
Summary	88
4. RESULTS	89
Introduction	89
Fathers Raising Children with Differing Intellectual Abilities	89
Demographic Descriptives	91
Participant Interviews	92
Participants- Who Were They?	93
Thematic Findings	95
Learning to Dance in the Rain	97

The Future is Always Unknown	98
Expectations Don't Change	99
Just Do What Needs Doing	100
The Power of Patience	101
Keep Moving Forward	102
Nurturing Uniqueness	104
Help Them Find Their Own Path	104
Ability-Specific Learning	105
Summary	107
5. DISCUSSION AND IMPLICATIONS	108
Summary of Findings and Discussion	108
Unique Children, Unique Fathers	108
Learning to Dance in the Rain	109
The Future Is Always Unknown	110
Expectations Don't Change	111
Just Do What Needs Doing	112
The Power of Patience	114
Nurturing Uniqueness	115
Reflecting the Theoretical	117
Piaget's Theory of Cognitive Development	117
Role Theory	119
Family Systems Theory	120
Differentiation of Self	120

Sibling Position	122
Chronic Sorrow	122
Multiple Intelligence Theory	123
Study Implications	123
Nursing Practice	124
Nursing Education	125
Future Nursing Research	126
Transferability	127
Study Strengths and Limitations	128
Conclusion	129
REFERENCES	130
APPENDICES	183
Appendix A: Federal Regulations Timeline: Increasing Access and Obtaining Rights	183
Appendix B: Eight Concepts of Bowen Family Systems Theory ...	186
Appendix C: Research Study Flyer	187
Appendix D: Informed Consent Document	188
Appendix E: Institutional Review Board Approval	192
Appendix F: Transcriptionist Confidentiality Agreement	194
Appendix G: Participant Screening/Background Information	195
Appendix H: Moderator Guide for Interviews	196
Appendix I: Permission for the Use of <i>Welcome to Holland</i>	197
Appendix J: Permission for the Use of <i>Dreams</i>	198

Appendix K: Institutional Review Board Review of Inclusion Error ..	200
VITA	202

CHAPTER 1

BACKGROUND OF THE PROBLEM

I saw an angel in the marble and carved until I set him free.

-- Michelangelo

Introduction

The concept of intelligence can be traced back thousands of years and is rooted in psychology (Cianciolo & Sternberg, 2004; Myers, 2010). The study of intelligence continues to intrigue scholars from cognitive and developmental psychology, sociology, organizational management, and psychometrics. (Cianciolo & Sternberg, 2004; Myers, 2010). For the last century researchers focused on measuring intelligence through a variety of methods and then began to investigate the corresponding brain location in use during testing as available technology advanced to allow visualization (Cianciolo & Sternberg, 2004). Although researchers have studied the intelligence of both males and females of all ages, most participants have been from Western society, and only in the past 2 to 3 decades have individuals living in other world regions become a focus (Cianciolo & Sternberg, 2004). Conspicuously absent from the literature, both in research and anecdotal manuscripts, is an exploration of how fathers' expectations about their children's intelligence affects their caregiver role. Fathers of at least two children, one with an intellectual disability and one without, certainly experience a reality different from their expectations after the birth of each child. Researchers have not explored how this understanding could affect the caregiving role of fathers and the health of their children.

History of Intelligence Research: Pre-20th Century

The earliest recording of individuals of different intellect was in the papyri of Thebes, Egypt in 1500 BCE (Scheerenberger, 1983). Intellectual disabilities were also documented before Plato and Aristotle, more than 400 years before the time of Jesus Christ. Those "deformed" or the offspring of the "inferior" were put away or killed according to the law of the time (Scheerenberger, 1983). Whether a child lived or died, was free or confined, depended largely on the beliefs of society at the time and the severity of the disability. Mental retardation was first defined from a legal perspective in 1324 (Scheerenberger, 1983). In the 15th century, Martin Luther described those with mental retardation as having "the Devil sitting in such changelings where their soul should be" (Scheerenberger, 1983, p. 32).

The earliest notation regarding what is now known as intelligence originated with Plato (Cianciolo & Sternberg, 2004). In 387 BCE he hypothesized the brain as the center of thinking processes (Gardner, 1983; Grasso, 2002). Plato wrote "knowledge is not given by the senses but acquired through them as reason organizes and makes sense out of that which is perceived" (Zusne, 1957, p. 6). Although a student of Plato, Aristotle hypothesized that these processes occurred in the heart (Gardner, 1983; Grasso, 2002; Turner, 1907). The philosopher and theologian Aquinas, in the 13th century, declared intelligence to be a gift from God stating "that for the knowledge of any truth whatsoever man needs divine help, that the intellect may be moved by God to its act." (Aquinas, trans. 1947, question 109, article 1). However, he also wrote that "human beings have the natural capacity to know many things without special divine revelation..." (Aquinas, trans. 1947, question 109, article 1).

During the 17th century Descartes, the "Father of Modern Philosophy", described the pineal gland as housing the mind and its thinking processes (Gardner, 1983; Skirry, 2008, p. 1). Although

signed anonymously, the most famous words attributed to him as translated into English, were, "I think, therefore I am" (Descartes, 1637/1960) and are believed to urge individuals to be skeptics of assumed truths and to search for one's own personal truth (Descartes, 1637/1960).

Unlike Descartes's belief in one mind and its one process, Kant, in the 18th century, was the first individual to hypothesize the existence of various facets of intelligence. One of the most influential philosophers of the 18th century, Kant described the individual mind as having processes to use *a priori* experiences to form new perceptions that differ for each individual (Cianciolo & Sternberg, 2004; Kant, 1785 /1993; Zusne, 1957). Rohlf (2010) described the critical component of Kantian philosophy as the belief that human autonomy could change all aspects of life and experience.

In 1869 Galton published *Hereditary Genius* in Great Britain stating his belief that intellectual abilities are biological in nature. In 1890 he developed the statistical techniques of correlation and regression to measure and rank the intelligence of his research subjects and further understand the interrelationships revealed in his studies of intelligence (Gardner, 1983; Tredoux, n.d.). Some of Galton's research subjects were fraternal and identical twins for whom he compared biological versus environment changes in intelligence (Tredoux, n.d.). He also coined the term "eugenics" to describe the process of improving the human race by keeping those with less desirable traits from procreating (Burch, 2009; Stoskepf, 1999). Eugenics was based on Mendelian heredity laws but was flawed in that criminality and pauperism were considered hereditary traits (Stoskepf, 1999). Galton defined this movement as "the study of all agencies under human control which can improve or impair the racial quality of future generations" (Galton, 1907, p. 200). Galtonian eugenics initially encouraged such strategies as marriage bans between races to control unwanted traits such as feeble-mindedness (Black, 2003). As Americans accepted the eugenics movement, it

became more negative as was apparent in the 20th century. Catell followed Galton with his own intelligence studies but abandoned this strategy for intelligence testing when results revealed no significant relationship between sensory input and intelligence (Minton, 1998).

As the use of Galton's methods waned, Binet, another psychologist, devised a new method of intellectual measurement, initiating the modern field of intelligence testing. Using 30 objective tests with increasing difficulty, Binet studied individuals with normal functioning minds and measured how those minds worked. Collaborating with Simon, Binet used this battery of tests to identify children in need of special education programs. By 1911 the Binet and Simon IQ test had been revised and included data on the “normal” values for young adults (Minton, 1998, Zazzo, 1993) with testing to determine if a child was at the level of (a) idiocy; (b) imbecility; or (c) morosity (Sheerenberger, 1983). Terman revised the Binet-Simon scale in 1916 and its 10 subscales, naming it the Stanford Revision of the Binet-Simon Scale, now in its 5th revision (SB5) (Plucker, 2007; Roid, 2011). With the work of Terman, Binet, and Simon, the study of intelligence moved into the beginning of the 20th century.

Intellectual Disabilities: Changing Societal Norms

Ever changing "best practices" are linked to the popular beliefs of the time and culture. From the time English colonists settled in the New World to current day, individuals who were different from the majority population were treated according to societal norms.

Pre-Colonial and 17th Century Beliefs

Mara Buck was the first known child with a disability in the New World colony of Virginia. Born in 1611, her guardian called her “very dull” in court papers filed in 1624 (Burch, 2009). In 1641, papers were filed in Massachusetts listing the minimal provisions all plantations were expected to provide for "idiots". By 1664 Boston provided housing for those with disabilities and by

1850 the State of Massachusetts had over 200 such facilities. Some argue the Salem Witch Trials of the late 17th century were intended to rid the community of those who were "different"-- either feebleminded or insane (Griffin, Peters, & Smith, 2007; Museum of Disability, 2010).

Eighteenth Century Familial Custodial Care to Societal Menace

In 1736 Bellevue Hospital in New York City opened to care for individuals unable to care for themselves. The first such hospital in Philadelphia opened in 1751 and provided separate areas for patients with intellectual disabilities and those with mental illness; by 1756 patients with intellectual disabilities were relocated to the basement of the facility and placed on display for a small fee (Burch, 2009). These and other "freak shows", that included those by P.T. Barnum of Barnum and Bailey Circus fame, continued until about 1940 and were provided as a form of entertainment (Griffin et al., 2007; Museum of Disability, 2010).

Connecticut passed a law in 1750, *An Act for Relieving and Ordering of Idiots, Impotent, Distracted, and Idle Persons*, requiring relatives to care for those unable to care for themselves. If an individual had no relatives, then the town in which the person lived took responsibility (Museum of Disability, 2010). Likewise, in 1769 a law was enacted in Virginia to ensure "idiots, lunatics and other people of unsound mind" would receive care (Scheerenberger, 1983). Also in Virginia, just 3 years prior to the signing of the Declaration of Independence, the first hospital opened solely for those "miserable objects" incapable of caring for themselves. The next similar facility was built in Lexington, Kentucky in 1824 (Nehring, 1999; Scheerenberger, 1983). In 1793 Philippe Pinel organized the first collective voice demanding the release of mental patients to gain more humane treatment for these individuals.

Nineteenth Century Humanitarianism to Isolation

During the early decades of the 19th century Americans began to accept that individuals with disabilities were genetically different from those without intellectual disabilities instead of possessed by spirits or the result of some wrong. They were cared for by others outside the family in institutions, schools, almshouses, or asylums as these facilities were established during this time for this purpose (Griffin et al., 2007). By 1818 the American Asylum for the Deaf and Dumb in Hartford, Connecticut provided the first officially recognized residential services intended specifically for individuals with intellectual disabilities in the United States (Burch, 2009; Nehring, 1999). Richard Poole, writing in 1825, described two kinds of mental deficiency: "one, in which there is an imbecility or weak state of all the faculties; the other, in which there is an imperfection or want of one faculty, or of several faculties" (Poole, 1825/1999). Several other authors throughout the 19th century used the terms "idiot", "idiocy", or "imbecility" to describe those with intellectual disabilities (Down, 1866; Howe, 1848/2001; Ireland, 1882/1997; Seguin, 1866/1997).

According to Wittman (2003) almost 17,500 United States residents were thought to have mental deficiencies in the mid 19th century. Some were even jailed as disgraces to the human race, sinners, or controlled by evil spirits, living with no heat, little food, and no furniture (Wittman, 2003). In March 1841 Dorothea Dix became an advocate for these individuals in Boston jails and almshouses (Burch, 2009). While teaching Sunday school to female inmates, Dix was exposed to the deplorable conditions in which these women lived; when she inquired why inmates were treated this way, she was told, "the insane do not feel heat or cold" (Viney & Zorich, 1982). After a multitude of court battles throughout the entire state of Massachusetts and eventually several other states and foreign countries, Dix dispelled the popular belief that, because individuals with intellectual disabilities could never be cured, inhumane treatment was acceptable (Bumb, n.d.). By

1880, she was directly responsible for the founding of 32 of the 123 institutions in the United States caring for and training those with intellectual disabilities (Viney & Zorich, 1982).

In 1850 Edouard Seguin moved to the United States, bringing with him years of experience training and teaching individuals with intellectual disabilities. He continued his work and by 1876 Seguin founded the Association of Medical Officers of American Institutions for Idiotic and Feebleminded Persons as a means of bringing together professionals working with these individuals (Biasini, Grupe, Huffman, & Bray, 1999). This organization later became the American Association on Mental Deficiency and then the American Association on Mental Retardation. In 2006, organizational membership voted and became the American Association on Intellectual and Developmental Disabilities (AAIDD) (AAIDD, 2010). Many of the training techniques Seguin pioneered are still in use today (Biasini et al., 1999).

In 1882 the United States government passed legislation barring immigration of any person who might prove to be a liability for society (Lombardo, 2010). The government constructed the buildings at Ellis Island to screen those immigrants requesting admission, turning those deemed unfit back home. During the Gold Rush in California, the number of immigrants increased dramatically. By 1917 Congress further described those barred from entry as “any convict, lunatic, idiot or person unable to take care of himself or herself without becoming a public charge” (Burch, 2009; Daniels, 2002) including those physically or mentally defective (Lombardo, 2010).

During the latter 2 decades of the 19th century institutions proliferated in the northern states. Usually built on rural land far from cities, they were easily overlooked and forgotten by society. Nehring (2003) wrote that construction occurred "away from the main roads so that people out taking drives would not have to see these individuals who were different" (p. 354). On February 10, 1893, in Dover, New Hampshire, a fire killed 40 patients at the Stratford County Insane Asylum.

The staff escaped but did not unlock the cell doors until it was too late (Burch, 2009). This incident among others added to the public outcry for more humane treatment of individuals with disabilities living in state facilities.

New York State passed the *State Care Act* at the end of the 19th century requiring the movement of indigent mentally ill patients from almshouses to state hospitals for treatment. Until this legislation was enacted, facilities for the mentally ill were called lunatic asylums. This act also provided funding for psychiatric research (New York State Education Department, 2010; Sheerenberger, 1983). By 1896, 13 such state hospitals were open in New York (New York State Education Department, 2010).

Although not legalized for another 8 years, Dr. Harry Sharp subjected inhabitants of an Indiana reform school to castration to alleviate masturbation and vasectomies prevented procreation among those he deemed likely to become criminals. Although not undertaken until after the turn of the century, Dr. Sharp advocated for the first sterilization law in Indiana as an integral part of the blossoming eugenics movement (Museum of Disability, 2010; Quiroz, 2008).

Twentieth Century Eugenics to Enlightenment

During the early 20th century treatment for those with intellectual disabilities ranged widely from direct care from family at home to moving into residential treatment facilities. Those considered treatable or "curable" received physical and chemical restraints (Nehring, 1999, 2003), hydrotherapy, and electric shock therapy (Maine.gov, 2010). Residential training schools also proliferated and individuals with intellectual disabilities were enrolled. The availability of the Binet-Simon and then the Stanford Revision of the Binet-Simon scale greatly influenced these training schools, and these testing methods were used to determine which children required special services (Sheerenberger, 1983). By 1910, 25 state institutions for "feebleminded" individuals housed 16,678

residents; by 1918, 43 such institutions housed 35,698, and by 1927, 51 state institutions were home to 49,791 (Burch, 2009).

When training had less than exemplary results in increasing intelligence scores, these schools became overcrowded, forcing many individuals back into special education classes in the community. Eventually, the training schools degenerated into severely overcrowded custodial living centers without any benefit of education or training for residents (Biasini et al., 1999), including the infamous Willowbrook State School in New York for mentally ill or delayed children. Six thousand residents, in a facility built for 4,000, were frequently injected with unknown liquids and allegedly used for hepatitis studies because they were expendable (DeBello, 2006; National Public Radio (NPR), 2008). According to DeBello some patients were given infected stool to eat while others were injected with purified virus preparations (2006). DuBois wrote describing his belief that some parents even allowed their children to be used in the study as it guaranteed their children's placement at the already over-capacity school (n.d.). DeBello summarized the beliefs of the time, "The mentality was to put these children where we can't see them... out of sight was also out of consciousness" (NPR, 2008, p. 1). One physician, Dr. Michael Wilkins, had just been fired for his outspoken advocacy while working in the facility. Dr. Wilkins provided an unconfiscated key to Geraldo Rivera (Disability Rights Center of Kansas, n. d.). This young reporter, and colleague, Jane Kurtin, went to the facility with a hidden camera, awakening the world to the institutional nightmares occurring there (NPR, 2008). Unfortunately, some children never left or were transferred and their families were unable to locate them (NPR, 2008; Slepian, 2008). Institutionalization at this and other state facilities continued throughout the first 4 decades of the 20th century.

Advocacy groups such as the National Association of Retarded Citizens began fighting for their rights, demanding training and not just places to live outside the view of society. Advocating for better conditions, Clifford Beers, a former institutionalized patient, published, *A Mind that Found Itself* (1907), describing in horrid detail the experience of living inside state and private mental institutions. Although some groups actively advocated for the rights of those institutionalized, others considered controlling the "spread" of intellectual disabilities through eugenics.

The first U.S. eugenics law was passed in Connecticut in 1896 (Burch, 2009), and forbid “epileptics, imbeciles, and the feebleminded” to marry (Goodheart, 2004, p. 106). Dr. George H. Knight initiated eugenics in Connecticut and believed in selective breeding among humans, preaching the prevention of increases in these undesirable groups (Goodheart, 2004). By 1907 the first forced sterilization law went into effect in Indiana (Black, 2003; Carlson, 2010; Cincinnati, 2005) and was law by 1909 in Connecticut (Lombardo, 2010). The Connecticut law included the sterilization of “inmates of State prisons and State Hospitals at Middletown and Norwich” (Laughlin, 1922, pp. 8) and those who “would produce children with an inherited tendency to crime, insanity, feeble-mindedness, idiocy, or imbecility” (p. 20). By 1913, these legal actions spread to 29 other states (Griffin et al., 2007; Ziegler, 2008). According to Black (2003), " The goal was to immediately sterilize fourteen million people in the United States and millions more worldwide—the “lower tenth”—and then continuously eradicate the remaining lowest tenth until only a pure Nordic super race remained" (p. xvi). In an effort to promote the eugenics movement, the film, *Black Stork*, made its debut in 1917. Featuring Dr. Harry Haiselden playing himself, the film told the story of one couple's decision to withhold surgical intervention from their baby, allowing it to die. Physicians often urged parents to withhold treatment for their disabled children as a means of cleansing the race (Black, 2003; Museum of diABILITY, 2010; ProCon, 2010).

In a 1927 United States Supreme Court decision, *Buck v. Bell*, Justice Oliver Wendell Holmes upheld the law of forced sterilization for those with disabilities, allowing eugenicists free reign (Black, 2003; Nehring, 1999). Justice Holmes (1927) wrote, "It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind...Three generations of imbeciles are enough" (p. 3).

As the director of the Eugenics Record Office from its inception in 1910 to its demise in 1939, Harry Laughlin was a major player in the eugenics movement. As such, he is credited with persuading legislators to create "modern" sterilization law (Black, 2003). This law *required* sterilization for the:

1) feebleminded; 2) insane (including the psychopathic); 3) criminalistic (including the delinquent and wayward); 4) epileptic; 5) inebriate (including drug habitués); 6) diseased (including the tubercular, the syphilitic, the leprous, and others with chronic, infectious, and legally segregable diseases); 7) blind (including those with seriously impaired vision); 8) deaf (including those with seriously impaired hearing); 9) deformed (including the crippled); and 10) dependent (including orphans, ne'er-do-wells, the homeless, tramps, and paupers) (Laughlin, 1922, p. 446).

It was not until after the end of World War II that the eugenics movement declined in popularity, largely due to America's distaste for its mass use by Hitler. However, it was not until the mid-1970s that its use completely disappeared. Lombardo and others described 33 states involuntarily sterilizing 60,000 "feebleminded" in an effort to increase the intelligence of the human race (Black, 2003; Griffin et al., 2007; Lombardo, 2010). However, in the middle of The Great

Depression, Congress passed and President Roosevelt signed the *Social Security Act*, establishing federal old-age benefits and providing monies to enable the states to assist children with disabilities and individuals who are blind (Federal Transit Administration, 2010).

Congress passed the *Hospital Survey and Construction Act (Hill-Burton Act)* in 1946 to build hospitals and community health centers, especially in rural areas (Hays, 2003; Thomas, 2010). As part of the agreement for obtaining grant monies from the Act, new facilities provided a percentage of free or reduced fee health care services. However, the Act did not specify a quantity or dollar amount each new facility pledged to provide. Therefore, these new facilities could not, or would not, handle the volume of individuals with disabilities requiring assistance (Federal Transit Administration, 2010; Hays, 2003).

Parent advocacy groups began forming in the late 1940s and 1950s and became a strong voice for their children. Groups such as the Association for Retarded Children and those advocating for children with specific conditions were influential in bringing attention to the inhumane conditions to which their children were subjected (Ambrosino, Ambrosino, Heffernan, & Shuttlesworth, 2007; Nehring, 1999, 2003). During a time when their popularity was at its peak, Roy Rogers's wife, Dale Evans Rogers, wrote *Angel Unaware* about their daughter's brief life living as a mongoloid (now called Down syndrome) and its accompanying heart anomalies (1953). Rogers described their choice to keep their daughter, Robin, at home, despite doctors' repeated urgings to place her in foster care or a nursing home (Rogers, 1953).

Increased access to technology assisted parent groups in the fight for their children's rights. Televisions became more popular allowing the general public to see the conditions that these children faced with their own eyes. Parents of children institutionalized in New York at Willowbrook State School filed suit (*New York ARC v. Rockefeller*) to improve the conditions at that

institution. It was a television broadcast depicting the deplorable conditions endured at the facility that engaged the general public. This press exposure, together with the lawsuit and the support of other advocacy groups, eventually incited the deinstitutionalization movement (San Francisco State University Disability Programs and Resource Center, 2010).

President John F. Kennedy made those with intellectual disabilities a priority for his administration, signing the Maternal and Child Health and Mental Retardation Planning Amendment to the *Social Security Act* on October 24, 1963. This legislation was the first significant federal funding to treat, prevent, and research causes of mental illness and retardation. Kennedy also initiated the National Institute of Child Health and Human Development, a part of the National Institutes of Health. On October 31, 1963, President Kennedy signed bill S1576 into law, the *Mental Retardation Facilities and Community Health Centers Construction Act*, authorizing \$329 million for construction of public and private nonprofit mental health facilities and community mental health centers in the United States (Federal Transit Administration, 2010; JFK Presidential Library & Museum, 2010). Throughout his short administration President Kennedy and his family changed the minds of Americans by stating, "The mentally ill and the mentally retarded need no longer be alien to our affections or beyond the help of our communities" (Kennedy, 1963, para. 9).

Another advocate group developed formal criteria by which to function about this time. Nursing practice standards were written in 1964 by the organization currently known as the American Association on Intellectual and Developmental Disabilities. Nurses advocated for better care of those with intellectual disabilities and the preservation of their civil rights (Nehring, 2003).

In addition to presidential, parent, and nurse advocacy, Burton Blatt represented concerned citizens in his call for reform. "There is hell on earth," wrote Blatt about a state institution in the northeast United States, "and in America there is a special inferno. We were visitors there during

Christmas, 1965” (Blatt & Kaplan, 1966, p. v). The author of *Christmas in Purgatory* (1966), he displayed pictures of life within the walls of an institution for the intellectually disabled. It was during this expose he humanized the patients and called for their deinstitutionalization (Burton Blatt Institute, 2007). Blatt returned to the same state institutions a decade later, and although the residents were cleaner and better cared for, they were still neglected (Taylor, 2006). In his book, *The Family Papers: A Return to Purgatory*, published after the return visits, he stated, "We need to empty the institutions. The quicker we accomplish that goal, the quicker we will be able to repair the damage done to generations of innocent inmates. The quicker we get about converting our ideologies and resources to a community model, the quicker we will learn how to forget what we perpetuated in the name of humanity" (Blatt, Ozolins, & McNally, 1979, p. 143).

The final group fighting for rights at this time included those with intellectual disabilities. With little money to support their advocacy they helped others navigate the legal requirements, spoke to groups about available services, and educated the public about conditions, treatments, and medications (Furlong-Norman, 1988). The Insane Liberation Front (Burch, 2009), The Alliance for the Liberation of Mental Patients, The League of the Physically Handicapped, We Are Not Alone, and Project Release fought for equal treatment, self-definition, autonomy, and full citizenship rights (Chamberlin, 1990, 1995; Disability Law Center, 2010; National Museum of American History, 2000). To assist in their fight, the National Center for Law and the Handicapped was founded at the University of Notre Dame in South Bend, Indiana, in 1970 and became the first legal advocacy center for individuals with disabilities in the United States (San Francisco State University Disability Programs and Resource Center, 2010).

Mobility was certainly an issue for those with disabilities. In 1968 Congress passed the *Architectural Barriers Act* making it illegal for federal buildings to remain inaccessible to people

with disabilities. According to the Federal Transit Administration, this was the first legislation addressing disability rights (2010). Many other pieces of legislation followed over the next 3 decades (See Appendix A for timeline of Federal regulations increasing access and securing citizen rights).

Throughout the 1960s and 1970s those inhabiting mental institutions were discharged and returned to society in hopes of preserving civil rights and improving living conditions. Many institutions closed altogether due to lack of funding and those for patients with intellectual disabilities were without adequate outpatient services (Koyangi, 2007; Torrey, 1997). This deinstitutionalization took place prior to improving services and ensuring housing for individuals with intellectual disabilities, leaving them homeless and prey to criminals (Koyanagi, 2007; Nehring, 2003). Although this process began in 1965, it was not until 1993 that policymakers allocated more state funds for community services and resources (Koyanagi, 2007). Thus, conditions were as bad as or worse than when those with intellectual disabilities were in state facilities.

In 1970 a lawsuit was filed in Alabama on behalf of a committed 15-year-old male. It became a landmark class action suit with three goals: "(1) establish a constitutional right to treatment on behalf of people with mental illness, (2) establish a constitutional right to habilitation on behalf of people with mental retardation, and (3) set minimum standards regarding safety, education, training, medication, nutrition, physical accommodations, staff/patient ratios, individualized treatment and aftercare" (Carr, 2004, p. 3). The judge granted all three requests, with a final decision in March 1972 setting standards of care for those living in institutions. Custodial care alone was no longer acceptable. The passage of the *Developmentally Disabled Assistance and Bill of Rights Act* established a "bill of rights" for individuals with developmental disabilities. This act provided federal funds for programs for the developmentally disabled and a series of rights for those in

institutions. The United States Congress passed the *Education for the Handicapped Act* or Public Law 94-142, in 1975, now titled the Individuals with *Disabilities Education Act* (IDEA). This Act guaranteed the appropriate education of all children with mental retardation and developmental disabilities from school age through 21 years of age. This law was amended in 1986 to guarantee educational services to children with disabilities ages 3 through 21 and provided incentives for states to develop infant and toddler service delivery systems. Today, most states guarantee intervention services to children with disabilities between birth and 21 years of age, but, as in the State of Tennessee, thousands are on waiting lists due to lack of funding or service providers. In June 2008 more than 6,000 children were waiting for services in Tennessee (Tennessee Division of Intellectual Disability Services, 2008).

The *Civil Rights of Institutionalized Persons Act* was passed by Congress in 1980. The Act allowed the United States Justice Department to act on behalf of the institutionalized in civil suits against the states. Civil suits could be brought against a state for violating the rights of institutionalized individuals in facilities for the mentally retarded and mental hospitals (Museum of Disability, 2010).

The International Year of Disabled Persons was celebrated in 1981 with ceremonies before the United Nations General Assembly. Governments world-wide were asked to promote the acceptance of the disabled into mainstream society. The theme was "full participation and equality" with an emphasis on the rights of the disabled in the larger society. The International Year of Disabled Persons would later be established as the National Decade of Disabled Persons between the years 1983 to 1992 by President Ronald Reagan (Museum of Disability, 2010).

The culmination of several decades of advocacy for basic human rights for those with disabilities was realized in the *Americans with Disabilities Act* of 1990 or PL 101-336 (U. S.

Department of Justice, 2009). Signed into law by George H. W. Bush, this act guaranteed that individuals with physical or mental disabilities would have the same rights as those without a disability, and made it illegal to discriminate against them. In fact, it required all public entities to make reasonable accommodations to ensure individuals with disabilities have equal access to housing, transportation, public services, and employment (U.S. Department of Justice, 2009). The first President Bush stated as he signed it, " I now lift my pen to sign this *Americans with Disabilities Act* and say: Let the shameful wall of exclusion finally come tumbling down. God bless you all" (U. S. Equal Employment Opportunity Commission, 2002, p. 1). The act was most recently amended in 2008 and signed by George W. Bush to offer broader protections for those with disabilities (U. S. Department of Justice, 2009).

At the turn of the 21st century several states, specifically Oregon, California, North Carolina, and Virginia, publicly apologized to current residents for forcing sterilizations on their family members with cognitive disabilities (Burch, 2009). Undoubtedly, this could do little to right the egregious wrongs forced upon state facility residents throughout the previous century. Currently, community care centers are closing and their residents are moving home, to group homes, or to semi-independent living arrangements. Those who can are staying at home with a parent or caregiver, receiving assistance from home care and government agencies if available. Despite recent improvements in father involvement, more often than not it remains the mother who assumes the primary caretaker role for the children (Dalirazar, 2007; Laughlin, 2010), especially those with disabilities (Herbert & Carpenter, 1994). As the primary caretaker, mothers remain the focus of research inquiries into these situations. In households where both parents are present and active caretakers, government researchers still consider the mother to be

the designated parent (Laughlin, 2010). In fact, in 2007 stay-at-home mothers numbered 56 million according to Kreider and Elliott (2009).

Research Need and Purpose

Fathers should have the opportunity to share their thoughts and feelings as only they can. The thoughts and feelings of fathers about their children may be different from the thoughts and feelings of mothers. Previous studies explored the perspectives of mothers and used those perspectives to represent the feelings of the mother-father dyad or the entire family (Dalirazar, 2007; Laughlin, 2010). Although more recent research includes fathers, no description of their role expectations and the realities they experienced after the birth of a child with intellectual disabilities have been presented in the literature. What do fathers expect prior to the birth of each of their children, especially about their children's intelligence? What do they do or how do they feel when reality differs from their expectations after the birth of a child with an intellectual disability? Do these fathers feel any differently about their parent role when expectations are unmet? The purpose of this study was to describe fathers' thoughts and feelings about becoming the father of both a child with an intellectual disability and one without.

Definitions

Intelligence

Intelligence is defined as the " (1) ability to learn or understand or to deal with new or trying situations; the skilled use of reason (2) the ability to apply knowledge to manipulate one's environment..." (Merriam-Webster, 2010, p. 1). Intelligence as defined by Howard Gardner is "the ability to solve problems, or to create products, that are valued within one or more cultural settings (1993, p. x).

Normal Intellect

Terman's scores for normal intellect varied from a low normal between 80 and 89, average intellect of 90-110, superior intellect between 111-120, 121-140 very superior intellect, and scores of greater than 140 correlated to genius or near genius intellect (Wechsler, 1944).

Expectations

Expectations refer to the implication of a high degree of certainty usually involving the idea of preparing or envisioning the future (Merriam-Webster, 2010).

Developmental Disability

The American Association on Intellectual and Developmental Disabilities uses the term developmental disability to encompass both physical and intellectual disabilities (2010).

Only children with intellectual disabilities are included in this study.

Intellectual Disability

According to the National Center on Birth Defects and Developmental Disabilities, a person is believed to have an intellectual disability if he or she has both "a significantly below-average score on a test of mental ability or intelligence" and "limitations in the ability to function in areas of daily life, such as communication, self-care, and getting along in social situations and school activities. Intellectual disability is sometimes referred to as a cognitive disability or mental retardation" (2005, para. 1). In 2002 the American Association on Intellectual and Developmental Disabilities added that to be classified as an intellectual disability the symptoms must "originate before the age of 18" (AAIDD, 2010).

Mental Retardation

Mental retardation is synonymous with intellectual disability (AAIDD, 2010). Mental retardation was once commonly used to describe someone who learns and develops more

slowly than others (Nemours Foundation, 2010). To have mental retardation is to have significantly subaverage general intellectual functioning, existing with deficits in adaptive behavior and manifested during the developmental period, adversely affects a child's educational performance (National Dissemination Center for Children with Disabilities, 2010). This terminology must be exactly the same because current federal and state laws since 1975 contain the term 'mental retardation'. That is the term used in law and public policy to determine eligibility for state and federal programs, including the Individuals *With Disabilities Education Act* (IDEA) (2004), Social Security Disability Insurance, and Medicaid Home and Community Based Waiver (AAIDD, 2010). In addition the term is used for citizenship and legal status, training and employment, income support, health care, and housing arrangements. For a permanent change in terminology to occur, Congress must change language in legislation (National Dissemination Center for Children with Disabilities, 2010).

Although changes in terminology in legal documents take time, terminology should change socially for several reasons. According to the American Association of Intellectual and Developmental Disabilities, these reasons include:

- It is less offensive to persons with disabilities.
- It is more consistent with internationally used technology.
- It emphasizes the sense that intellectual disability is no longer considered an absolute, invariable trait of a person.
- It aligns with current professional practices that focus on providing supports tailored to individuals to enhance their functioning within particular environments.

- It opens the way to understanding and pursuing 'disability identity', including such principles as self-worth, subjective wellbeing, pride, engagement in political action, and more (2010, p. 1, FAQs).

Finally, the American Psychological Association (2000) describes four levels of intellectual disability in *The Diagnostic and Statistical Manual of Mental Disorders, 4th edition, Text Revision*, based on Standard Binet scores: (1) 50-55 to 70 as mild, (2) 35-40 to 50-55 as moderate, (3) 20-25 to 35-40 as severe, and below 20-25 as profound disability. About 85% of individuals with an intellectual disability fall into the mild category (American Psychological Association, 2000).

Significance to Nursing

In the past many fathers of children with intellectual disabilities found it easier to leave the parental role altogether than to adjust their caretaking behaviors to the demands of their new reality (Bowen, Dysinger, & Basamania, 1959; Gerard & Siegel, 1950; Herbert & Carpenter, 1994; Lidz, Fleck, & Cornelison, 1965). The findings of this study may assist in changing the prenatal and postpartum education and support nurses provide to fathers, regardless of the intellectual ability of their children. If nurses have a better understanding of the father-child relationship and the adjustments necessary to adequately provide for each child's diverse social, developmental, and physical needs, the better prepared these fathers will be to cope with their new reality. These families are maneuvering through complex care needs in an even more complex healthcare system. The assistance provided by nurses encountering these families can make the situation safer and less complicated.

Summary

From 2006 to 2008 about 10 million school-age children lived in the United States with some form of developmental disability (Szabo. 2011). Of those, about 28 children per 1,000, or 3,388,000, age 18 and under, had some form of intellectual disability (Centers for Disease Control and Prevention (CDC), 2010) caused by a genetic or chromosomal condition such as Down syndrome, factors affecting brain development during pregnancy such as maternal alcohol intake, birth complications such as fetal anoxia, or health problems after birth from trauma, malnutrition, or poisoning (National Dissemination Center for Children with Disabilities, 2010). In the State of Tennessee in 2006, 124,277 children, or 15.24% of children from birth through age 21, required educational assistance through programs funded through the *Individuals with Disabilities Education Act* (United States Department of Education, 2008). Intellectual disabilities are the most common type of developmental disorder (CDC, 2010). Although information about disabilities abound, terminology and best practices for the care of individuals with disabilities remain controversial. It is only through the continued study of differences in intellectual capacity that this will change.

The study of intelligence has a long history rooted in the social sciences. The work exploring intelligence includes both those with disabilities and those without; the work has advanced as technology affords additional methods by which to study cognitive function.

Until recently individuals of all ages with intellectual disabilities were treated as subhuman and denied citizen rights. Some were used as research subjects so scientists could learn about the components of human intelligence or the lack thereof. Once society eliminated the "shameful wall of exclusion" (U. S. Equal Employment Opportunity Commission, 2002, p. 1), the majority of these individuals thrived with proper care and respect. As this field of study expands, involving those with

intellectual disabilities and the family situations in which they reside, so too must nursing science expand to bring the best evidence-based care to this population.

CHAPTER 2

LITERATURE REVIEW

Introduction

From the turn of the 20th century theories of human intelligence, family functioning, traditional and nontraditional parenting roles, and familial adaptation to the birth of a child have received much attention in the literature. To assist in organizing 20th century intelligence research in this chapter, the many theories are organized into metaphors with examples of each type briefly discussed. The literature about each theory underpinning childhood cognitive development and fathers' roles and possible experiences are also briefly discussed. Finally, this review is concluded with an overview of the literature focusing on the siblings of children with cognitive disabilities and mothers and fathers in their roles as caregivers both historically and more recently.

General Intelligence Research in the 20th and 21st Centuries

With the increasing technology available in the 20th century, e.g., computed topography, positron emission tomography, and magnetic resonance imaging, scientists have made remarkable discoveries in studying general intelligence (Cianciolo & Sternberg, 2004). The studies have been published with such rapidity experts in the field have classified each area into distinct categories using metaphors as descriptions (Cianciolo & Sternberg, 2004).

Geographic Metaphor

The metaphor encompassing the oldest theoretical work discussed in this section is the geographic metaphor used to describe those theories that map the mind. According to Cianciolo and Sternberg (2004) one or more factors affect an individual's cognitive ability, and the theories

within this category differ mainly in the number of factors they map. Spearman (1927) described two factors affecting intelligence and called the first general mental energy, *g*, describing those capabilities measured by overall intelligence testing, and the other specific, *s*, measuring each specific ability such as reading comprehension (Cianciolo & Sternberg, 2004; Spearman, 1904; Williams, Zimmerman, Zumbo, & Ross, 2003). This was the first psychometric theory of intelligence (Embretson & McCollam, 2000; Williams et al., 2003) and within his writings Spearman described his beliefs that a person must have *general* intelligence to perform a *specific* task (Catell, 1968). Prior to this work Spearman also developed the multivariate statistical method of factor analysis that was heavily influenced by Galton's work (Horn & McArdle, 2007; Williams et al., 2003). Those who disagreed with Spearman posited general intelligence, *g*, involved multiple abilities stemming from different intellectual capabilities (Cianciolo & Sternberg, 2004). Included within this group were psychologists such as Thurstone (1938), Thomson (1939), and Guilford (1956); they explained that specific factors affected intelligence, describing from 7 to 180 factors (Cianciolo & Sternberg, 2004; Guilford, 1982). For example, Thurstone described seven factors including "verbal comprehension, verbal fluency, arithmetic computation and problem solving, memory, perceptual speed, inductive reasoning, and spatial visualization" (Cianciolo & Sternberg, 2004, p. 6). Those who disagreed with Spearman's two factor theory and the specific intelligence theories by Thurstone, Thomson, and Guilford developed hierarchical theories of the geographical metaphor (Cianciolo & Sternberg, 2004).

The hierarchical theories place general intelligence at the top and the intelligence necessary for specific abilities lower in the hierarchy (Cianciolo & Sternberg, 2004). The first positing this theory was Spearman's student, R. B. Cattell, who continued working on intelligence theory after Spearman's death (Plucker, 2007). With his student, J. L. Horn, Cattell

derived the theory of fluid and crystallized intelligences, describing fluid abilities, *Gf*, as those allowing quick reaction and problem solving and crystallized abilities, *Gc*, as those learned and acquired through brain development (Cianciolo & Sternberg, 2004; Horn & Cattell, 1967).

After Cattell, Carroll (1993) continued working on hierarchical intelligence, calling his work *three-stratum theory*. The hierarchy begins with narrow abilities such as perception and computational abilities, then fluid abilities including learning and memory, and, at the top of the hierarchy, general intelligence (Cianciolo & Sternberg, 2004). Other individuals working within this area included Ackerman, Guttman, Lohman, Marshalek, and Snow.

Computational Metaphor

Scientists studying intelligence by comparing a computer's central processing unit to how the brain functions are classified in this metaphor (Cianciolo & Sternberg, 2004). As early as 1923 these scientists included Spearman whose work continued throughout the remainder of the 20th and into the 21st century.

The two-factor theory of intelligence is attributed to Spearman, but he is also known for first describing the brain as moving through a set of processes as a person thinks (Cianciolo & Sternberg, 2004; Spearman, 1923). Cianciolo and Sternberg (2004) described three approaches to this method of studying differences in levels of intelligence: cognitive training, cognitive components, and cognitive correlates.

Hunt, Frost, and Lunneborg (1973) introduced the cognitive correlates approach in 1973 (Cianciolo & Sternberg, 2004). They attempted to correlate psychometric testing scores with tasks such as the speed of retrieving dictionary definitions and comparing letters by upper and lower case (Hunt et al., 1973), achieving only moderate correlations in their work (Cianciolo & Sternberg, 2004; Weiner, Freedheim, Reynolds, Schinka, & Miller 2003). More recently, Engle,

Tulhoski, Laughlin, and Conway, Hambrick, Kane, and Engle, and Kyllonen and Christal have contributed to the work in the cognitive correlates approach, looking at the relationship between working memory and general intelligence (Cianciolo & Sternberg, 2004).

Sternberg (1977) posited the cognitive-components to separate complex task performance into component informational processing steps. For example, for an individual to process the analogy "HORSE is to SADDLE as BIKE is to ???", individuals must work through several cognitive processes such as first determining the meaning of each word, then determining the relationship between the first two words, before finally contemplating the identity of the missing word, SEAT (Cianciolo & Sternberg, 2004; Sternberg, 1977). At best, the results showed weak relationships or the exact opposite results of those expected (Weiner et al., 2003).

Training in a particular cognitive process is the focus of the cognitive-training approach to determining why individual intelligence differs. Campione, Brown, and Ferrara (1982) introduced this approach as an attempt to determine if intelligence test scores would increase if an individual completed training in an area affecting the cognitive function being tested. For instance, if someone wanted to work on the speed at which mathematical computation occurred, then the person practiced math computation. Campione et al. (1982) found weak relationships in most cognitive processes after training in those areas was completed.

Biological Metaphor

Cianciolo and Sternberg (2004) use this metaphor to describe studying intelligence using advanced technology such as electroencephalograms (EEG), functional magnetic resonance imaging (fMRI), and positron emission tomography (PET). The goal in this approach is to measure differences in brain volume and map the brain to determine how individuals differ in intelligence. More specifically, scientists such as Vernon, Wickett, Bazana, and Stelmack

(2000) and Deary and Caryl (1997) measured electrocortical activity, cerebral blood flow, glucose metabolism, and activity levels in each area of the brain when specific tasks were completed or particular learning occurred (Cianciolo & Sternberg, 2004). Scientists have used these techniques only since the 1980s, and similar studies will continue to proliferate as these technologies become more powerful and others arise.

Examples of this method of studying the differences in intelligence are easier to understand using each of the aforementioned technologies, EEG, fMRI, and PET scanning. When an individual performs a task such as product recognition, and an EEG is completed each time this occurs, each of these EEGs are averaged together, combining to form a measurement called P300 (Cianciolo & Sternberg, 2004). The researchers posited that the faster the recognition occurs, the higher the P300 activity and the higher the level of intelligence (Vernon, Wickett, Bazana, & Stelmack, 2000). However, this was not always the case (Cianciolo & Sternberg, 2004).

Haier (2003) posited that individuals performing better on intelligence tests would be more efficient in their requirements for glucose and blood flow than those with lesser intelligence. Tested with the assistance of a PET scanner, this was not shown to be true in all cases. Sometimes those with better performance required greater blood flow and glucose uptake than those less intelligent (Haier, 2003).

The fMRI has also been used to determine levels of activity in the brain during "intellectually demanding tasks" (Cianciolo & Sternberg, 2004, p. 14), with the same inconclusive results as with the PET scanner (Bunge, Ochsner, Desmond, Glover, & Gabrieli, 2001). However, these scientists demonstrated increased activity levels in the frontal lobes of the brain, allowing the individual to more easily resist distractions (2001).

Epistemological Metaphor

This metaphor describes theories in which knowledge acquisition is the central focus (Cianciolo & Sternberg, 2004). Thus, Piaget and those extending his work are categorized in this metaphor by Cianciolo and Sternberg (2004). As discussed in more theoretical detail, Piaget (1952) described knowledge acquisition as occurring in four stages, age-dependent, and culminates by 15 to 16 years of age. After Piaget's death, neo-Piagetian scientists addressed the shortcomings of the original theory (Cianciolo & Sternberg, 2004). For instance, Piaget did not include any developmental stages past adolescence (Basseches, 1984; Commons et al., 1990; King & Kitchener, 1994; Kohlberg, 1969, 1981; Perry, 1970), nor did he discuss how social, psychological, and moral differences can affect knowledge acquisition (Harter, 1999; Kegan, 1982, 1994; Noam, Powers, Kilkenny, & Beedy, 1990; Selman, 1980).

Sociological Metaphor

Cianciolo and Sternberg (2004) use the sociological metaphor to describe the study of how society affects knowledge and its acquisition in the individual. Individuals living within a particular society are affected by those they encounter through language, sights, sounds, and attitudes (Cianciolo & Sternberg, 2004). For example, no one can live in a vacuum, and in moving through tasks of a normal day an individual would see, hear, experience, and internalize the attitudes of others that would affect that individual's knowledge. Vygotsky (1978), a social cognitive theorist and psychologist, was the major influence in this perspective and described individuals as using tools, e.g., language and behavior, in what he termed *zones of proximal development* to affect the thinking of others. As suggested by Vygotsky, the zone of proximal development (ZPD) is the difference between the skills individuals, especially children, can do independently and those skills they can accomplish with assistance. It is in this ZPD that an

individual's learning can emerge as independent knowledge (Morris, 2008) with the assistance of others in the same environment. Thus, children can only reach their full potential with repeated social interaction (Vygotsky, 1978).

Others working within this perspective included Feuerstein (1980), who worked directly with Vygotsky, Heath (1983) who studied differences in home and school definitions of intelligence and how different ways of speaking and living in society affect acquisition of school knowledge, and Okagaki and Sternberg (1993) who studied differing ethnic definitions of intelligence and how different ethnic groups mediate learning for their children at home and at school (Cianciolo & Sternberg, 2004). Tharp and Gallimore (1988) used a four-stage model of ZPD to show how children develop speech and language. The research of Newman, Griffin, and Cole (1989) suggested the activities included in the ZPD reflect the cultural background of the learner. Goodman and Goodman (1990) studied the effect social use of language has on literacy. Okagaki (2001) also studied the effect family systems and the internal cultures they create have on academic performance (Cianciolo & Sternberg, 2004). For example, Okagaki (2001) found that children with parents who had high expectations for scholastic achievement and who worked with their parents on school activities and homework were more likely to exhibit higher intellectual performance.

Anthropological Metaphor

Culture shapes societal views of intelligence (Benson, 2003; Bulut, 2008; Cianciolo & Sternberg, 2004). Anthropological methods of studying intelligence focus on the cultural belief systems in which individuals are enmeshed and their effects on how intelligence is viewed by those within the culture. For example, in Western culture it is expected that an individual who values intelligence spends substantial time in formal learning environments and continues this

quest throughout life (Bulut, 2008). Nisbett (2004) described the Western view of intelligence as outcome oriented in that only the end results of being successful matter. In Eastern cultures, however, intelligence is internally focused, and children are expected to learn social relationship skills and how to solve social problems (Nisbett, 2004).

Berry (1974; Georgas, van de Vijver, & Berry, 2004) was one of the first to posit that the level of intelligence is culture specific. Greenfield (1997) expressed concern that intelligence tests contrived in Western cultures were likely culturally biased and should be more culture neutral to be more accurate measures of intelligence. Others followed with studies of their own including Gill and Keats (1980) who described intelligence in Australia as based on adaptive ability in new situations and Serpell (1982) who described Zambian intelligence as based on social skills and cooperation.

More recently Poortinga and van de Vijver (2004) described their belief that multiculturally sound intelligence testing was possible. It is the exam administrator who must carefully consider how each question will be construed in different cultures.

Systems Metaphor

The most recent work in intelligence and its components use the systems metaphor. Systems theory was first developed by von Bertalanffy as he witnessed the process fragmentation brought by the Machine Age of the late 19th and early 20th centuries (Bertalanffy Center for the Study of Systems Science, 2010). As defined by Cianciolo and Sternberg (2004), "a system has multiple interdependent parts and its successful overall function is a result of the harmonious interaction of these parts" (p. 25). Cianciolo and Sternberg posit systems theories of intelligence differ in the breadth of behaviors considered as well as specifically considering cultural and environmental effects on the meaning of intelligence. It could be argued that

Thorndike (1920) was one of the first individuals to suggest multiple intelligences because he proposed three aspects of intelligence, e.g., abstract intelligence comprising the abilities tested on an intelligence test; mechanical or practical intelligence, describing how individuals make rapid decisions to meet the demands of the environment; and social intelligence, the ability to interact interpersonally (Greenspan & Granfield, 1992). Thus, Thorndike's concept of intelligence differed from Spearman's theory of general intelligence, or *g*.

The scientists who most recently represent systems intelligence theories include Sternberg (1997, 1999), Ceci (1996), and Gardner (1983, 1999). Sternberg (2003) included three parts of intelligence comprising the system: analytical, creative or synthetic, and practical intelligence. Analytical intelligence is the intelligence tested most frequently in academia and on tests like the Stanford-Binet Intelligence Test (Sternberg, 2003). Creative or synthetic intelligence describes context-dependent critical thinking or using current knowledge to cope with another problem in a novel situation (Sternberg, 2003). Sternberg's (2003) third component of his system of intelligence was described as practical intelligence or the ability to adapt to rapid changes in daily life. Cianciolo and Sternberg (2004) described Sternberg's theory as a compilation of geographic, computational, and anthropological metaphors in that all three abilities must be used and the individual must be cognizant of any shortcomings to be intelligent. In brief, shortcomings in one area of intelligence must be overcome by the strengths in another area for the individual to become and remain successful in life.

Ceci's work (1996) combines all aforementioned metaphors of intelligence into a bioecological model of multiple and complex cognitive potentials that enable knowledge acquisition and growth. It is these potentials that allow individuals to adapt previously acquired knowledge to new situations. In brief, Ceci (1996) described all intelligence as context

dependent and varying in complexity when necessary to enable the individual to function and learn in the current culture. Ceci, Bronfenbrenner, and Baker (1988) stated, "The context in which cognition takes place is not simply an adjunct to the cognition, but a constituent of it" (p. 243).

Perhaps the most widely used systems theory of intelligence is Gardner's (1983, 1999) work describing multiple intelligences. This theory uses tenets from the geographic, biological, and anthropological metaphors, combining them into at least eight intelligences (2004). In his 2006 book, *Multiple Intelligences: New Horizons*, Gardner describes human "cognitive competence" as "a set of abilities, talents, or mental skills..." or "intelligences" (p. 6). He further describes these intelligences as being possessed in some degree by all "normal individuals" (p. 6). What if an individual, by the Stanford-Binet standard, is not "normal"?

The original intelligences described by Gardner (1983) included musical, bodily-kinesthetic, logical-mathematical, linguistic, spatial, interpersonal, and intrapersonal. More recently Gardner (2006) added naturalistic intelligence, using it to describe the ability to recognize differences among and within species. In the last 2 decades individuals looked beyond the mainstream to find other possibly more effective methods of educating at all levels of intelligence (Hearne & Stone, 1995). These multiple intelligences have been, and continue to be, integrated into multiple educational curricula, levels, and projects, among them Key School in Indianapolis, New City School in St. Louis, Project Spectrum, the Practical Intelligence for Schools Project, Project Zero's Arts PROPEL, Project Zero's Project SUMIT, and Harvard's Project Zero (Gardner, 2006; Hearne & Stone, 1995). Programs still functioning are The Key School and the New City School. The Key School in Indianapolis is a school for children kindergarten through eighth grade; enrollment is voluntary. Instructional strategies are based on

all seven of the original intelligences, and "not just the linguistic and logical-mathematical intelligences that are the focus of most schools" (North Central Regional Educational Laboratory, 2011). The New City School in St. Louis is also based on the original seven intelligences, plus the additional eighth added in 2006, and its teachers and staff believe, "Multiple Intelligence theory is the tool through which students learn and engage with the curriculum and by which the material comes alive for each student" from preschool to graduation (New City School, 2011, para 4).

Programs no longer active include the Practical Intelligence for Schools Project, and all the Harvard Project Zero projects, which were Arts PROPEL, Project Zero's Project Spectrum, and Project SUMIT. The Practical Intelligence for Schools Project was a joint investigation led by Sternberg, Okagaki, and Jackson in 1990. A joint project by Harvard and Yale Universities, it combined Gardner's MI and Sternberg's triarchic theories of intelligence into a curriculum to develop practical intelligence enabling students to move through the mental processes for practical application to novel and recurrent situations (Sternberg, Okagaki, & Jackson, 1990). Project Spectrum was "based on the belief that each child exhibits a distinctive profile of different abilities, or spectrum of intelligences" (Harvard Project Zero, 2010, para. 3). The project was implemented from 1984 to 1988 to develop curriculum for young children in preschool, kindergarten, and first grade, assisting them to determine their particular spectrum at any early age. ARTS Propel was a 5-year project to assist children in grades 7 through 12 in Pittsburg to determine their artistic strengths through "production, perception, and reflection" (Project Zero, 2010, para. 3). Project SUMIT was funded for 3 years, 1997 through 2000, to identify schools in the United States using MI theory, documenting the achievements, and

promoting effective implementation of MI theory-based curricula in additional schools (Harvard Project Zero, 2010).

Work continues in both the psychometric aspects of the theory with the Multiple Intelligences Profiling Questionnaire, 3rd revision (Tirri & Nokelainen, 2008), and in visualizing changes in blood supply to various areas of the brain as different tasks such as depth perception (Corbetta & Shulman, 2002) and musical interpretation (Visser, Ashton, & Vernon, 2006; Zatorre, 1999) are undertaken. Researchers have also investigated multiple intelligence theory's application to educational simulations in applied sciences such as nursing and dentistry (Alinier, 2008; Clark, 2007; Galloway, 2009; Howard, Stewart, Woodall, Kingsley, & Ditmeyer, 2009; Rourke, Schmidt, & Garga, 2010), in Web-based learning (Gutierrez, Perri, & Quackenbush, 2006; Li, Porter, Hopkins, Clarke, & Irons, 2001; Riha & Robles-Piña, 2009), and at all education levels (Mills, 2000; Taylor, 2008).

Describing all intelligences, Gardner (2006) states, "My belief is that these multiple human faculties... are to a significant extent independent of one another... as research with brain damaged adults demonstrates particular faculties can be lost while others are spared" (2006, p. 22). What does this mean for children who have an intellectual disability? Do one or more of these intelligences emerge as "normal" or even exceptional in these children? When asked to describe their children, will fathers describe differences in and among them that will assist in answering these questions?

It is the systems view of intelligence, specifically multiple intelligences that serves as a springboard for the current study. It is only one of many theories possibly affecting the expectations and realities of the relationships fathers experience with their children. Subsequently, other pertinent background theories are described.

Theoretical Foundations

The current study has fundamental groundwork that may be reflected in the data obtained from the participants. These theories are discussed in detail to render a greater understanding of the literature in this area. Although other theories exist in the literature with possible bearing on the outcome, the most likely are included in this review.

Piaget's Theory of Cognitive Development

As a developmental psychologist and "genetic epistemologist", Jean Piaget studied how intelligence forms and develops across the lifespan (Piaget, 1968, p. 1). While working with Binet and Simon to study children's answers to questions on intelligence tests, Piaget studied "both the formation and the meaning of knowledge" (1968, p. 1) to understand how the mind learns. No other developmental psychologist has had more influence on the study of cognitive development during the 20th century than Piaget (Atherton, 2010b; Cherry, 2010; Gardner, 1983; Kodat, 2002).

Huitt and Hummel (2003) described Piagetian theory as having two parts: (1) coming to know through assimilation with and accommodation to the environment and (2) the actual stages of normal growth and development. Piaget described assimilation as changing external stimuli to fit current internal knowledge and accommodation to changing internal knowledge to understand external reality (Atherton, 2010a; Siegler & Ellis, 1996). An example of assimilation: a young child sees a picture of an infant, but does not recognize the infant as herself as a baby because the mental picture she has of an infant does not match the reality of herself in the actual picture. In older children, the child would adapt the mental image of an infant to assimilate or incorporate the reality of the actual picture. Assimilation and accommodation influence each other as the child matures and becomes more experienced in mental imaging.

According to Piaget in normal development a young child should first go through the sensorimotor stage of development in which all knowledge acquisition occurs with physical activity and the senses as the child experiences everything new (Cherry, 2010; Lutz & Huitt, 2004). At approximately 2 years of age the child moves into the next stage, called preoperational, as language acquisition begins. This stage represents the period in which the child's thinking is egocentric and limited to concrete information (Lutz & Huitt, 2004). Following successful completion of this stage, transition to the third stage occurs at about 7 years of age and is termed concrete operational. During this time, the child begins to think logically but is still unable to understand or form abstract thought (Lutz & Huitt, 2004). Formal operational thought begins at about 11 years of age and involves the ability to hypothesize and think abstractly. Children also develop morals, begin to develop a sense of self, and are able to determine how others should behave (Lutz & Huitt, 2004). Piaget believed adolescents should complete this stage of cognitive development by age 15 (Lutz & Huitt, 2004; Piaget, 2008), but research has concluded this assumption is not necessarily the case, as age and physical development do not indicate successful stage completion for cognitive development (Busen, 2001; Eylon & Lynn, 1988; Houde, 2000; Renner et al., 1976). In those with cognitive disabilities the disparity between age and cognition may be even more apparent.

Cognitive disabilities affect the speed at which children move through Piaget's stages and whether children reach the later stages at all. Piaget stated that cognitive development in those with disabilities follows "the same rule of application, [but] follows a much slower rhythm and remains forever unfinished" (Piaget & Inhelder, 1947, p. 403). Payton (2008) suggested that the ability to develop cognitively depends on the ability to experience the environment according to Piagetian theory. If a child's disability affects the ability to experience aspects of the environment

then cognitive development will be adversely affected. According to this paradigm it is imperative for caregivers to expose their children to as many elements of the environment as possible (Hodapp, 1998; Payton, 2008). To determine the cognitive level of those with disabilities after additional environmental exposure, some describe Piaget's task-related conceptual testing as superior to psychometric-related intelligence testing (Hodapp, 1998; Woodward, 1979).

In the current study differences in cognitive development will most likely become evident as participants discuss their children's intelligence. The disparity between each participant's two children will largely depend upon the severity of cognitive disability in the father's affected child. What will these fathers perceive as their role in each child's development? Will they describe their roles with each child differently? Will they see environmental exposure as central to each child's development? The interviews may provide some insight in this area. Further foundational understanding is possible by discussing role theory and its application to fatherhood and child development.

Role Theory

As described by Biddle (1986), roles are central to society as they describe members' social positions that carry inherent expectations for behavior from self and others. Beginning in the 1930s in sociology and anthropology, scholars of import describing role theory included George Herbert Mead who introduced the concept of role taking, and Ralph Linton and Robert Merton who studied how individuals behaved to satisfy their "socially designated obligations" (Turner, 1996, p. 582). They determined that roles and the expectations therein varied dependent upon the positions occupied, the interactions with others, and the context or situation in which individuals found themselves (Turner, 1996). Biddle suggested five major models of role theory,

but the two that best approximate the issues in this study are functional role theory and symbolic interactionist role theory.

Functional role theory. As Biddle (1986) conveyed, functional role theory describes behavior expected within a certain role behavior that is largely dependent upon societal expectations for that role. Thus, the way people act in certain roles is deemed either appropriate or inappropriate based on societal norms about the function of that role. When applied to the study participants, functional role theory postulates that each father will describe his own behavior in the paternal role similarly.

Symbolic interactionist role theory. Interaction between a person and society is the central concept of symbolic interactionist role theory. In this theory the behavior an individual displays in a role is dependent upon the behavior of others in that role, and then the behavior is modified as necessary (Mead, 1934). Mead (1934) posited that children take on roles as they mature and as they see others successfully function in those and complementary roles. Children begin role-taking by first entering the preparatory stage in which they imitate others in the role but have no understanding of the societal expectations of the role. Role play involves further imitation without visualizing the adult self in the role. As children move through the game stage, they take on a multitude of different roles, adapting them to both conform to expectations and make them unique (Mead, 1934). This imitation-adaptation behavior then continues throughout the life cycle.

In addition to having role expectations and imitating roles as an avenue for learning, role theory also focuses on reciprocal roles as central to the socialization process (Newman & Newman, 2009). Individuals assuming opposite roles, meaning student to teacher or child to parent, are paramount to appropriately enacting the roles involved. The "patterned

characteristics" of a role must be matched to its complementary role to successfully play that role (Newman & Newman, 2009, p. 72). Much like actors in a two-person play, without the second actor to speak the opposite lines, the first actor is superfluous. A man has expectations for the father role. According to role theory, fathers must have a child to play the reciprocal role for fathers to assimilate the characteristics of their role. What does a father do when his child cannot or will not reciprocate?

Family Systems Theory

Ludwig von Bertalanffy held that the mechanistic perspective of the Machine Age brought disintegration and disorganization to every aspect of society (Bertalanffy Center for the Study of Systems Science, 2010). His general systems theory (GST) encouraged the scientific community to look upon society as something other than smaller pieces of a whole. Similarly but separately from GST, Murray Bowen encouraged scientists to view families in much the same way. He developed family systems theory (FST) to guide clinical interventions during his time working as a psychiatrist with hospitalized schizophrenic patients (Miller, Anderson, & Keala, 2004). Considered one of the major theoretical advances of the 20th century, Bowen's work continued through Freeman and Kerr in the field of psychology following Bowen's death in 1990. This theoretical model is referenced in family nursing texts as the profession moved to a family and community focus (Harmon-Hanson & Kaakinen, 2005). In contrast to Freud's focus on individuals, Bowen described behavior as being rooted in familial relationships (Harmon-Hanson & Kaakinen, 2005; Kane, 2005). By understanding these family relationships, it is possible to understand current situational conflicts experienced by the family. Brown describes Bowenian theory as focusing on the patterns within families developing over generations to reduce the anxiety produced by unresolved conflicts (1999). Considered a single emotional unit

in Bowen FST, the family unit must become aware of how it functions and increase the levels of independent thinking within the constraints of the family (Brown, 1999; Van Wormer, 2007).

This means each individual member must be his or her own person and not rely on family members in a codependent relationship (Van Wormer, 2007).

The eight facets of Bowen FST are 1) differentiation of self, 2) triangles, 3) nuclear family emotional system, 4) family projection process, 5) transmission process, 6) sibling position, 7) emotional cutoff, and 8) societal emotional process (Bowen, 1978) (See Appendix B). Bowen described the central concept in his theoretical model as the differentiation of self (Bowen, 1976; Knauth, 2003; Miller, Anderson, & Keala, 2004). To become differentiated meant that a person is capable of keeping emotional influences from affecting intellectual thinking (Knauth, 2003) within the confines of the familial emotional unit. A completely differentiated person is a member of the family but is a separate self who can hold "beliefs, opinions, convictions and life principles" (Rabsteijnek, n.d., p. 6) while the undifferentiated family member "operates by rules, customs, and expectations..." (Rabstenjnek, n. d., p. 6). Bowen (1978) posited that poorly differentiated families have an increased likelihood of recurrent conflict within that family. Indeed, "the greater the fusion, the more [one] is vulnerable to physical illness, emotional illness, and social illness, and the less [one] is able to consciously control [one's] life" (Bowen, 1978, p. 305). The goal, therefore, is to work through familial difficulties, and use Bowenian theory to assist in avoiding future conflicts by becoming a family of differentiated selves. Differentiation then contributes to the stability of the entire family.

Another of the eight major facets of FST is the birth order or sibling position of family members. Bowen (1976) used Toman's work (1976) to describe sibling position within the family as having positive and negative effects on familial roles, conflict, and daily functioning.

Birth order affects both parents and children in a family insomuch as first born children tend to be leaders and younger children tend to be followers (Gilbert, 1999). Should an older sibling in a birth family marry an older sibling from another birth family, these parents may compete for the leadership position. As followers, younger children from different birth families who marry may find themselves unable to make decisions readily, leading to conflict and underachievement (Gilbert, 1999).

Birth order was first posited by Adler as having an influence on personality traits in 1927. According to Toman (1976) the offspring of these individuals mentioned above are also affected by their birth order in much the same way. He stated that first born children tended to be overachievers and those born second tended to take less responsibility. Those born in the middle tended to be the peace-makers within a birth family, thus function in this fashion in their own families as adults. Current researchers have also found these assertions to be true (Hartshorne, 2010). However, as results have been contradictory in the investigation into the effects of birth order on personality, researchers continue to explore this question (Hartshorne, 2010).

In the literature authors from the social sciences applied Bowen family systems theory to a myriad of research interests. It has been used successfully to explore the level of differentiation among church congregations (Haeger, 2008); adolescents (Diver, 2006; Knauth, Skowron, & Escobar, 2006; Rosen, Bartle-Haring, & Stith, 2001); those undergoing cardiac rehabilitation (Newberry, 2007); those undergoing substance abuse treatment (McNight, 2008; Selm, 2002; Walker, 2007); grandparents rearing grandchildren (Coman, 1995); college students exploring career options (Keller, 2008); first-year college students (Buettner & Bartle-Haring, Andrews, & Khurana, 2010; Mushrush, 2008); individuals with depression (Hooper & DePuy, 2010); the therapist's own family members (Titelman, 1987); family grieving a death (Gaal,

2006; Titelman, 1987); ethnic groups (Skowron, 2004); homeless youths (Slesnick, Bartle-Haring, & Gangamma, 2006; Slesnick, Bartle-Haring, Dashora, Kang, & Aukward, 2008); couples undergoing therapy (Bartle-Haring, Glade, & Vira, 2005; Bartle-Haring & Lal, 2010; Glade, 2005; Knerr & Bartle-Haring, 2010; Sabetelli & Bartle-Haring, 2003); those remarrying following divorce (Cauley, 2008), individuals with chronic anxiety (Bosholm, 2004; Carpenter, 1990); individuals undergoing inpatient psychiatric treatment (Hasselle, 1994); victims of child abuse (Skowron & Platt, 2005); individuals suffering burnout in the workplace (Chambers, 2009; Hanson, 1998); those with same-sex parents (Coates & Sullivan, 2005); survivors of a disaster such as 9/11, those with fibromyalgia (Murray, Daniels, & Murray, 2006); adult children of divorced parents (Akers-Woody, 2004); employees of the United States government (Boers, 1999); intergenerational attachment problems (Diamond & Doane, 1994); and families wherein one member has a disability (Bragg, Brown, & Berninger, 1992; Cottone, Handelsman, & Walters, 1987; Ho & Keiley, 2003).

Chronic Sorrow

In 1961 Solnit and Stark wrote about maternal reactions to the birth of a child with congenital defects. They described those reactions as similar to mourning a child who had died. Olshansky (1962), building on their work in the field of social work, described this phenomenon, chronic sorrow, as a means of explaining these reactions. The description included the recurring experience of grief that parents have as they mourn the loss of their “perfect child” (Olshansky, 1962). Olshansky posited this concept to also describe the phenomenon surfacing repeatedly when children with disabilities deviate from normal or expected growth and development patterns (1962). Additionally, he defined chronic sorrow as “the permanent day-by-day dependence of the child, the interminable frustrations resulting from the child’s relative

changelessness, the unaesthetic quality of mental defectiveness, the deep symbolism buried in the process of giving birth to a defective child” (Olshansky, 1962, p. 191). Searl used his own experiences as the father of a child with a disability to affirm the description of chronic sorrow as posited by Olshansky (Searl, 1978). His description included “shock, guilt, and bitterness that never disappear from the parent’s emotional life” (Searl, as cited by Lindgren, Burke, Hainsworth, & Eakes, 1992, p. 29).

From 1962 into the 1980s, only a handful of studies have focused on populations of cognitively impaired or chronically ill children. Since that time the research and informational literature in this arena has flourished. Wikler, Wasow, and Hatfield (1981) completed the first study of chronic sorrow from the fields of social work and psychology. More studies investigating chronic sorrow have followed describing the concept from the perspectives of parents, mostly mothers, of children with a myriad of illnesses and disabilities such as cystic fibrosis, diabetes, and physical and cognitive disabilities (Atkinson, 1994; Britton, 1999, 2002; Buschman, 1988; Cameron, Snowden, & Orr, 1992; Clubb, 1991; Coffey, 2006; Copley & Brodensteiner, 1987; Damrosch & Perry, 1989; Eakes, 1995; Fraley, 1986; Fraley, 1990; Gravelle, 1997; Hobdell, 2004; Hobdell & Deatrlick, 1996; Hummel & Eastman, 1991; Hurley & Levitas, 2004; Johnsonius, 1996; Kearney & Griffin, 2001; Krafft & Krafft, 1998; Kratochvil & Devereaux, 1988; Krausz & Meszaros, 2005; Lowes & Lynne, 2000; Mallow, 1994; Mallow & Bechtel, 1999; Meleski, 2002; Northington, 2000; Pejler, 2001; Phillips, 1991; Scornaienchi, 2003; Seiderman & Klein, 1995; Shumaker, 1995; Stephenson & Murphy, 1986; Wikler, Wasow, & Hatfield, 1981), the bereaved (Burke, Eakes, & Hainworth, 1999; Chomicki, Sobsey, Sauvegeot, & Wilgosh, 1995; Kaunonen, Paivi, Paunonen, & Erjanti, 2000; Miller, 2000), caregivers of adults with chronic illnesses and disabilities, (Cooney, 2004; Eriksson & Svedlund,

2006; Hainsworth, 1995; Howard, 1998; Lindgren, Connelly, & Gaspar, 1999) and those chronically ill or injured themselves (Eakes, 1993; Hainsworth, 1994; Hainsworth, Eakes, & Burke, 1994; Hayes, 2001; Lichtenstein, Laska, & Clair, 2001; Lindgren, 1996) Using both qualitative and quantitative inquiry, these studies provided existential evidence of the phenomenon of chronic sorrow. In the more than 40 years since it was first identified, over 600 articles-- research and descriptive-- have contributed to the evolution of this concept from “a broad, simple description of psychological reaction to a tragic situation to a more specific description of recurring periodic sadness that is permanent and progressive” (Lindgren et al., 1992, p. 30).

Teel (1991) completed the first concept analysis of chronic sorrow. She defined chronic sorrow as a situation of recurrent sadness in which “a relationship of attachment is disrupted following an event that renders a loved one forever changed from the hoped-for child or from the known person” (Teel, 1991, p. 1311). Lindgren et al. (1992, p. 31) used the Walker and Avant (1995) method to complete another concept analysis enumerating the characteristics of the concept with operational definitions. The defining characteristics include:

- A perception of sadness or sorrow over time in a situation with no predictable end,
- Sadness or sorrow that is cyclic or recurrent,
- Sadness or sorrow that is triggered by internal or external events and brings to mind a person’s losses, disappointments, or fears, and finally
- Sadness or sorrow that is progressive and can intensify.

Based on these defining characteristics, Eakes, Burke, and Hainsworth (1998) posited a middle-range theory of chronic sorrow. This theoretical work further defines the antecedents to

chronic sorrow as being the “ongoing disparity created by the loss experience, rather than the ongoing nature of the loss situation” (Eakes et al., 1998, p. 181). This work culminated in the theoretical model of chronic sorrow.

These characteristics and subsequent revised definitions of chronic sorrow guide the current study as a possible foundation for the experiences fathers will express. Review of the research literature follows to elucidate the current state of the science exploring mothers as caregivers, the experiences of siblings of those with intellectual disabilities, fathers as caregivers, and the roles males expect as they become fathers in contemporary society.

Current State of the Science

The literature in the area forming the foundation for the current study involves the main characters of family life-- the mothers, fathers, and siblings living with children affected by an intellectual disability. The researcher briefly describes the recent literature describing commonalities found in mothers caring for children with intellectual disabilities. Siblings of children with intellectual disabilities are also included in this discussion to afford a deeper understanding of how they can be impacted when living in a home with an affected brother or sister. Finally, a review of the literature focusing on fathers concludes this chapter to enable a complete understanding of the focal disparity found in the literature between mothers and fathers.

Mothers as Caregivers in Recent Literature

The variations in syndromes and intellectual disabilities alone require continual investigation into their nuances. Scientific advances into the human genome also support a better understanding of the genesis of such disorders and disabilities, giving rise to new avenues of exploration. In addition, each affected child reacts to and functions differently with a

particular disorder, as does each family into which a child is born. Historically, research into intellectual disabilities and the families affected by those children focused mainly on the mother and her perceptions, as she most commonly served as the primary child caretaker. Although this practice of using the mother as chief informant is slowly changing, a brief overview of the recent literature available in this area follows to facilitate an understanding of the complexity of the mother-child relationship.

As any parent can attest, having a baby and becoming a parent is a stressful event even under the best circumstances. Having a baby born or a young child diagnosed with an intellectual disability must increase that stress exponentially (Seltzer et al., 2009). Child behavior, social support, and coping strategies are posited as possible correlates to feelings of maternal stress when parenting a child with an intellectual disability. Lloyd and Hastings (2008) found avoidance coping to be a major factor in stress perception using both cross-sectional and longitudinal designs. Not surprisingly, mothers also experienced more stress when they had less support with child care activities (Guralnick, Hammond, Neville, & Connor, 2008; Shin & Viet Nhan, 2009; Skok, Harvey, & Reddihough, 2006). Maternal stress was also found to be inversely proportional to the child's behavior (Eisenhower, Baker, & Blacher, 2005; Hassall, Rose, & McDonald, 2005; Tomanik, Harris, & Hawkins, 2004) meaning as their children's behavior worsened, mothers reported an increase in their stress levels. Positive locus of control, or a mother's perception of having situational control, mediates the amount of stress mothers experienced caring for these children (Hassall, Rose, & McDonald, 2005; Paczkowski & Baker, 2007; Walls & Fletcher, 2009). Finally, feelings of well-being were inversely proportional to the mother's perception of stress (Skok et al., 2006).

In addition to using maternal reports of well being as a measure of stress associated with raising a child with an intellectual disability, researchers studied how other variables such as coping and locus of control affected reports of well being. Kim, Greenberg, Seltzer, and Krauss (2003) found that emotional coping strategies resulted in reduced well being in these mothers; problem-focused coping heightened reports of well being and improved the overall maternal-child relationship. Positive maternal emotions, however, were reported as a determining factor in improved family adjustment to having a member with an intellectual disability (Trute, Benzies, Worthington, Reddon, & Moore, 2010). Maternal reports of well being were also directly proportional to positive perceptions of locus of control, paid work outside the home, and lower socioeconomic class (Emerson, Hatton, Llewellyn, Blacker, & Graham, 2006; Lloyd & Hastings, 2009; Olsson & Hwang, 2006; Shu & Lung, 2005).

A frequent topic involving children with severe intellectual disabilities describes the perpetual, unchanging child-parent relationship (Jennings, 1987). The parent never has the opportunity to experience his or her affected child as an independent adult, and must reconcile never experiencing events such as the child getting married or having children. As an example of this phenomenon, Todd and Jones (2005) used qualitative interviews to investigate the maternal experience of parenting a child with an intellectual disability during middle adulthood. The experience was thematically described by the investigators as “looking at the future—seeing the past”. Although the child and mother have both changed, the maternal responsibilities have not; they are seemingly endless.

The aforementioned studies are examples of the voluminous research focusing on maternal perceptions of raising children with intellectual disabilities. Although studies focusing

on fathers are lacking in this area, siblings of intellectually disabled children have garnered more research interest, and an overview of pertinent literature follows.

Siblings of Children with Intellectual Disabilities

Much like fathers, siblings of children with disabilities have taken a back seat to the mother and affected sibling dyad. Meyer (2007) describes unaffected siblings as the "traditionally underserved family members" who only recently, in the past 3 or 4 decades since the advent of family systems theory, have enjoyed additional research interest (p. 42; Lindsey & Stewart, 1989; Vadasy, Fewell, Meyer, & Schell, 1984). Considering siblings is imperative as these individuals will have enduring interactions with the affected child, most likely long after the parents are deceased (Cicirelli, 1982; Lobato, Kane, & Plante, 2006; Mandelco, Olsen, Dyches, & Marshall, 2003; Meyer, 2007). Through the lens of family systems theory, as siblings grow up together, family routines and the children's overall development, through their behavior, social skills, and emotions, can be affected (Brody, 1998). Dunn (1983) describes specific sibling aspects of learning social roles as reciprocity and complementarity. Reciprocity is role playing, like actors in a play, saying their lines opposite each other; Complementarity describes how siblings tend to be opposites but "mutually supply each other's lack" (Merriam-Webster, 2011). Through these vital roles siblings play for one another, Nielsen et al. (2010) stated, because of the dearth of information on these sibling relationships, it is imperative for researchers to more closely study the variables affecting these siblings.

Similar to research on fathers, previous studies on relationships between those siblings intellectually disabled and those typically developing usually relied on maternal reports of behavioral issues or overall adjustment (Pilowsky, Yirmiya, Doppelt, Gross-Tsur, & Shalev, 2004; Sari, Baser, & Turan 2005; Van Riper, 2000). If the father was involved in the research

endeavor, several studies explicated paternal and maternal reports of sibling adjustment and overall wellbeing often differed (Berge, Patterson, & Rueter, 2006; Cuskelly & Gunn, 2006; Hastings et al., 2005; Stoneman, 2005). Overall, however, studies focusing on these families appear to fall into three main categories; researchers have concluded the sibling or siblings of a child with a disability are impacted negatively, positively, or not at all in terms of the sibling's overall psychological health during childhood and into the adult years.

Researchers present both qualitative and quantitative results and report siblings experiencing broad negative effects from having a brother or sister with an intellectual disability. Even without considering the variables of age, birth order, and gender, researchers postulate only harmful effects from this sibling relationship. Investigators described increased behavioral problems and anxiety (Barrera, Fleming, & Khan, 2004; Fisman, Wolf, Ellison, & Freeman, 2000; Giallo & Gavidia-Payne, 2006; Hastings, 2003; Mulroy, Robertson, Aiberti, Leonard, & Bower, 2008; Seltzer, Greenberg, Krauss, Gordon, & Judge, 1997; Seltzer, Greenberg, Orsmond, & Lounds, 2005), increased stress as the adult caretaker of an adult sibling with an intellectual disability (Greenberg, Seltzer, Ormond, & Krauss, 1999), psychological distress such as depression and sleeping problems (Bagenholm & Gillberg, 1991; Bischoff & Tingstrom, 1991; Del Rosario & Keefe, 2003; Hastings, 2007; Silver & Frohlinger-Graham, 2000), embarrassment and guilt about their normal development (Grossman, 1972), social adjustment problems such as difficulty coping and stress with new situations (Hannah & Midlarsky, 1985; Houtzager et al., 2004; Seltzer, Greenberg, Krauss, Gordon, & Judge, 1997; Singhi, Malhi, & Pershad, 2002), behavioral, emotional, and social problems from caregiver load (Barrera, Chung, & Greenberg, 2002; Labay & Walco, 2004; Neece, Blacher, & Baker, 2010; Petalas, Hastings, Nash, Lloyd, & Dowey, 2009), complaining about preferential treatment received by the affected

child (Barrera, Fleming, & Kahn, 2004), feeling deprived and resentful of the extra time and attention the affected child required (Batte, Watson, & Amess, 2006; Britton & Moore, 2002; Hannah & Midlarsky, 2005; Mulroy, Robertson, Aiberti, & Bower, 2008; Powell & Ogle, 1985; Waite-Jones & Madill, 2008), and having an impaired self-concept (Dyson, Edgar, & Crnic, 1989; Singhi, Malhi, & Pershad, 2002; Wolf, Fisman, Ellison, & Freeman, 1998). It would be plausible that current study participants will reveal the same issues when discussing the realities of fathering both a child with and one without intellectual disabilities. However, as the literature is divided in this area, positive effects from living with children with intellectual disabilities could also be an expectation. Although studies reporting positive effects are not as prolific as those reporting negative effects, many researchers found positive outcomes for siblings living with a child who has an intellectual disability. Siblings have written anecdotally about the relationships they enjoyed, and currently still enjoy, with their disabled siblings. Werman, age 13, described life with his sister with autism and an intellectual disability as mostly positive but with a little frustration at times (2009). He states after realizing at age 11 his sister was being bullied at school, "I started participating in community service that helps other kids with disabilities" (2009, p. 82). At age 12, he began helping kids with disabilities, and "it made me feel good to make them feel like they had a friend... and [when] I see them smile, it makes my day" (p. 82). His sister Emily "teaches me many life lessons. And I would not change my sister, because she is perfect in her own way" (2009, p. 82).

Researchers have concluded that having a sibling who has a disability gives children better coping skills and they show a maturity not evident in other children their age (Dykens, 2005; Grossman, 1972; Hannah & Midlarsky, 2005; Houtzager et al., 2005; Labay & Walco, 2004; Macks & Reeve, 2007; Taunt & Hastings, 2002), are more empathetic, kinder, and more

involved with the family (Dallas, Stevensen, & McGurk, 1993; Kaminsky & Dewey, 2002; Nielsen et al., 2010; Van Riper, 2000), seem to take pleasure in and experience a sense of achievement when assisting with caregiving (Sharpe & Rossiter, 2002; Stoneman, 2005; Waite-Jones & Madill, 2008), show better social adjustment (Baumann, Dyches, & Braddick, 2005; Dallas, Stevensen, & McGurk, 1993; Mandelco, Olsen, Dyches, & Marshall, 2003; Pilowsky, Yirmiya, Doppelt, Gross-Tsur, & Shalev, 2004; Skotko & Levine, 2006), and are more empathetic towards others, even outside the family (Benderix & Sivberg; 2007; Cuskelly & Gunn, 2006).

Other researchers have concluded that having a sibling with an intellectual disability has no effects on the typically developing child in the family (Dyson, 1999; Eisenberg, Baker, & Blacher, 1998; Gold, 1993; Levy-Wasser & Katz, 2004). Although a number of studies have focused on siblings with intellectual disabilities, little work delving into fathers' perspectives exist. As the current study focused on paternal perspectives, more detail is given in this area of research to illustrate the current state of the science.

Fathers as Caregivers and their Expectations

Fathers have had a tumultuous history in providing care for their children. Historically, when fathers worked in and around the home farming or producing goods for sale, they assisted with discipline and other child rearing activities. Once the Industrial Revolution began, fathers worked as factory laborers, often leaving before children awakened and returning after bedtime (Carpenter, 2005). In the current state of financial unrest in the United States, more fathers are unemployed, working from home, or working fewer hours, enabling more childcare responsibilities (Kepcher, 2010).

Fathers as the foci of research studies has increased over the past 40 years as societal expectations for males has changed with the differences between male roles from the previous generation so drastically altered in the next (American Psychological Association (APA), 2010; deFalco, Esposito, Venuti, & Bronstein, 2008; MacDonald & Hastings, 2010; Simmerman, Blacher, & Baker, 2001). Societal expectations for fathers have changed from father as patriarch, protector, and absolute ruler of the family prior to the late 20th century, to one that is more participative and adaptable to changes in society (Carpenter, 2005). As women have become more highly educated, mothers are more likely to work outside the home, becoming less dependent on male economic support (APA, 2010). This maternal absence from home has made it necessary for fathers to participate more frequently in childcare and household maintenance tasks. Until this change in role expectations, mothers were the most commonly studied members of the family, often answering for their husbands and children (MacDonald & Hastings, 2008; Quinn, 1999; Seligman & Darling, 2007). Mothers were more accessible during regular daytime hours, and fathers were often not considered accessible or important in the caretaking role (Ballard, Bray, Shelton, & Clarkson, 1997; Herbert & Carpenter 1994; MacDonald & Hastings, 2010; McConkey, 2004; West, 2000). Ballard called fathers the "invisible parent" (1994, p. 4). However, they became more active in the caretaking role as mothers entered the workforce, paternal work weeks shortened, and role expectations changed so that mothers were not automatically expected to take primary responsibility for child rearing (APA, 2010; Giulio & Carrozza, 2007; MacDonald & Hastings, 2010). A National Institute of Child Health and Human Development (NICHD) funded study found that fathers were more active in childcare activities when they worked fewer hours, had higher self-esteem, when mothers worked more, and when the children were male (NICHD, 2000).

Family systems theory also expanded researchers' focus to the entire family and each individual member therein to gain significant information about the family's overall functioning (MacDonald & Hastings, 2010). Additionally, in the past few decades child development experts found fathers to be as important as mothers in their children's overall growth and development, so fathers were encouraged to spend more time with their children for this positive impact (APA, 2010; Bronte-Tinkew, Carrano, Horowitz, & Kimukawa, 2008; de Falco, Esposito, Venuti, & Bornstein, 2008; Lamb, 1997; Lewis & Lamb, 2003; Tamis-LeMonda & Cabrera, 1999; Ricci & Hodapp, 2003). This increase in paternal time commitment included fathers of children with intellectual disabilities as deinstitutionalization, beginning in the 1980s, allowed these children to remain in the home (MacDonald & Hastings, 2010).

Studies and anecdotal literature described positive results when children experience increased paternal involvement, particularly when that involvement was by choice. These positive results included more and better relationships with peers and family, lower incidence of delinquency and substance use, and overall higher self-esteem and satisfaction with life choices. However, the opposite was also found to be true. If the increase in paternal involvement resulted from a sense of obligation or unemployment, these positive results were not realized (Fluori, 2005; Roggman, Boyce, Cook, Christiansen, & Jones, 2004; Shears, Robinson, & Emde, 2002; Williams & Radin, 1999).

In research involving children with intellectual disabilities MacDonald and Hastings (2010) found these societal changes have done little to encourage paternal inclusion, except when compared to maternal opinions. Thus they stated, "Much progress is still needed to clarify and reach a consensus on how "fathers and the fathering role are defined in research" (2010, p. 487). Soutl (1998) and West (2000) described fathers of disabled children as marginalized and

underrepresented. Seligman and Darling (2007) concurred with this assessment finding fathers among the least studied family members regardless of focus.

Prior to 1990 researchers completed eight literature reviews about fathers of children with intellectual disabilities; Hornsby (1995) described eight assertions summarizing the findings of these reviews (Bristol & Gallagher, 1986; Brotherson, Turnbull, Summers, & Turnbull, 1986; Lamb, 1983; McConachie, 1982; Meyer, 1986a; Meyer, 1986b; Meyer, Vadasy, Fewell, & Schell, 1982; Price-Bonham & Addison, 1978).

- Fathers adapt better to daughters with disabilities than to sons with disabilities;
- Adaptation is more difficult if the disability is severe;
- Feelings of stress are related to the child's age;
- Adaptation is related to social support;
- Adaptation is related to the father's personality;
- Feelings of stress increase as social class, income, and education level decrease;
- Many fathers of children with disabilities experience depression and personality issues; and
- More fathers experience marital problems and leave the situation when a child with a disability is involved (Hornsby, 1995).

Hornsby's study found evidence for only two previously-held assertions: (1) the father's ability to adapt is related to his personality characteristics, and (2) fathers feel more stress with lower income and education levels (1995). As more than 20 years have passed since these reviews, will current study participants' descriptions of the realities encountered provide evidence for any of these eight previously-held assertions?

If fathers were included in research studies completed after 1990, the research focus was most likely fathers' strong emotional response to the diagnosis of an intellectual disability (Herbert & Carpenter, 1994; Hornby, 1992; Kearney & Griffin, 2001; Towers & Swift, 2006), their stress and coping responses (Glidden, Billings, & Jobe, 2006; Hastings et al., 2005; Heller, Hsieh, & Rowitz, 1997; Olsson & Hwang, 2001; Saloviita, Itälina, & Leinonen, 2003; Shin et al., 2006; Sloper, Knussen, Turner, & Cunningham, 1991), and concern over the lifetime needs of the child (Bray, Skelton, Ballard, & Clarkson, 1995; Hornby, 1995; Lamb & Laumann-Billings, 1997; Pelchat et al., 1999; Towers & Swift, 2006). Herbert and Carpenter also found fathers of children with intellectual disability often felt a sense of failure when not able to be strong for and overtly supportive of the child's mother (1994). Fathers in the Herbert and Carpenter study also reported finding it overly stressful discussing the child, and coped with the birth of these children by working additional hours and consuming more alcohol.

Fathers in other studies described their role expectations before and after having their first child (Halle et al., 2008; Henwood & Procter, 2003; Holland, 1995; Stanley-Stevens & Seward, 2007) and the difficulty accepting the unmet expectations experienced in their father role (Bielawska-Batorowicz & Kossakowska-Petrycka, 2006; Fox, Bruce, & Combs-Orme, 2000; Luce, 2009; May, 1982), although these were fathers of typically developing children. One study described the unmet expectations of fathers of children experiencing spinal cord injuries, using the family systems perspective (Murray, Sullivan, Brophy, & Mailhot, 1991). No studies described the role expectations and the realities encountered by fathers who have parented intellectually disabled children as well as typically developing children. In the present study, this gap is addressed by examining the expectations and realities fathers of both typically developing and intellectually disabled children experience.

Summary

The fathers participating in this study have expectations of their role as a father and how they should present that role to others around them. Will they describe their expectations largely from a functionalist standpoint? Does the birth of a child with a cognitive disability force the father to adapt as in the symbolic interactionist view of role theory? How will they describe the reality encountered?

The tenets of Bowen's theory, specifically sibling position and differentiation, may have bearing on fathers' expectations of their children's intelligence and the father roles they anticipate. How are they able to cope with the disparity when they have a child with a cognitive disability? Does the birth of a child with a cognitive disability make the same impact regardless of the order in which the children are born? It is possible fathers have positively influenced the familial unit to become more differentiated, less emotional, and more contemplative when making decisions about their children's care.

Are fathers of children with *both* intellectual impairments and those developing normally more attune to the possibility of multiple intelligences? Do fathers experience an ongoing sense of loss when their experiences with their children are different from their previous expectations? Are they able to negotiate their feelings to cope with the differences without regrets? If using positive coping strategies, these fathers need support and reassurance. If fathers have the tools to cope, will triggers lose their potential for causing chronic sorrow throughout the fathers' lifetimes? If fathers have more ongoing nursing support and improved interpersonal relations, will they experience fewer unstable periods? It is possible the study may assist in answering these questions.

Will fathers in the current study describe their typically developing children as not being affected by the child with intellectual disability? Do fathers' realities include a role in making the sibling relationship the best for both children? Does the possibility of multiple intelligences in each child keep the disability from affecting the typically developing child? Only the participant fathers can answer these questions. Chapter 3 describes the methods through which the researcher will interview them.

CHAPTER 3

RESEARCH METHODS

Introduction

The purpose of this study is to characterize fathers' expectations of their father roles as well as their experiences in these roles fathering a child with and a child without intellectual disabilities. Through this study health care providers at all levels can better anticipate the needs of fathers and prepare them for the reality of having children with differences in cognitive abilities. The investigator describes the methods to obtain and protect participants, data management and analysis techniques, as well as how rigor was established. Results will provide evidence for practical nursing interventions.

Study Design

A qualitative descriptive design was chosen due to the paucity of information available about fathers' expectations and the reality encountered when they have children with and without intellectual disabilities. Qualitative inquiry is appropriate when little is known about the phenomenon of interest (Wood & Ross-Kerr, 2011). It is also the method of choice when the researcher "aims to understand the social world from the viewpoint of respondents..." (Myers, 2000, p. 1) and when the connection to the real world can only be made by the participants (Wood & Ross-Kerr, 2011). As qualitative data collection is an iterative process, it is also expected the study focus may change slightly as each participant is interviewed, using the data from the previous participant to inform the next interview (Miles & Huberman, 1994).

Population and Sample

As a type of purposive sampling, Wood and Ross-Kerr (2011) describe network sampling as a nonprobability sampling method useful when it may prove difficult to find individuals

meeting the inclusion and exclusion criteria set for study participants. Therefore, network sampling was employed to find one father, and then the researcher asked for other potential participants. The first two potential participants were fathers already known to the researcher. If one or both of these individuals agreed to participate, each was asked for other potential participants. In addition to network sampling and word-of-mouth sample generation, the researcher requested access to other potential participants with the assistance of three regional and state agencies, Supporting and Training for Exceptional Parents in Tennessee, the Tennessee Disability Coalition, , and the East Tennessee Technology Access Center. All three agencies specialize in assisting those with disabilities and their families.

To improve access to fathers meeting inclusion criteria, the researcher contacted Support and Training for Exceptional Parents in Tennessee (STEP-TN, asking for their assistance in locating fathers. This statewide agency states "parents possess unique information about the development, nature, and needs of their children. STEP believes that parents can make an important contribution to the education of their children. Therefore, parents can and should become effective partners with professionals in planning and implementing appropriate programs. STEP provides support to parents when they request help, training, and information during this process" (STEP's Philosophy, para. 1, 2011). The researcher described the study purpose and inclusion criteria for fathers and asked staff for assistance in finding possible participants. Once they agreed to assist, the researcher sent fliers with study purpose, target participant, and researcher contact information to Ms. Karen Harrison, the STEP-TN Executive Director, who forwarded through electronic mail to their members via listserv.

The researcher also contacted the Tennessee Disability Coalition, located in Nashville. According to the Coalition's main Webpage, "The Coalition is an alliance of organizations and

individuals who have joined to promote the full and equal participation of men, women and children with disabilities in all aspects of life. We work together to advocate for public policy that ensures self-determination, independence, empowerment, and inclusion for people with disabilities in areas such as accessibility, education, healthcare, housing, and voting rights" (para. 1, 2011). After describing the study purpose and inclusion criteria, the researcher asked for assistance from Ms. Donna DeStefano, Assistant Director, in sending the approved research flier to their member organizations to disseminate to their members as potential participants. This flier listed researcher contact information with a brief description of the research purpose and participant inclusion criteria (Appendix C).

In addition to the aforementioned avenues, the researcher also contacted the East Tennessee Technology Access Center (ETTAC) to request assistance. The ETTAC is a regional nonprofit organization specializing in providing information about and access to devices assisting in mobility and independent living for individuals with disabilities and their families. The researcher followed the same procedure requesting assistance getting fliers to their membership to recruit potential participants. Ms. Lorrie Crockett put a portable document format (pdf) of the study flyer on the agency's Facebook page and sent it to their listserv as an announcement in the newsletter.

The target population for this study included all fathers in Tennessee having at least two children - one with a diagnosed intellectual disability and one cognitively intact- whose ages are between 2 and 16 years. The researcher avoided those fathers of children newly diagnosed as infants as well as those nearing transition to adulthood. Fathers of children newly diagnosed with intellectual disabilities are working through intense feelings and enormous amounts of information. The researcher focused on father's experiences after the initial time of adjustment

to the diagnosis is passed. Fathers of children nearing adulthood are undergoing other transitional concerns such as financial, changes in living arrangements, and caretaking arrangements because the child will most likely outlive his or her parents (Murphy, Clegg, & Almack, 2011). It was expected the sample of fathers would reside in or around Knox County, Tennessee. Participant enrollment continued until after data saturation was reached. Other inclusion and exclusion criteria in place for the study were:

- Each participant was living with his children, whether the children were adopted, step, or biological, at least half time. Using family systems theory, this lifestyle stability should best elicit information about how each father's experiences were affected by others in the family unit.
- Each of the father's children discussed with the researcher was living.
- Participants were English-speaking.
- Participating fathers were married to the children's mother, divorced, or widowers.
- Race and religious preferences of the participants were not considered.

Protection of Participants

Under the ETSU Guidelines on the Responsible Conduct of Research, the researcher used due care to ensure the privacy and confidentiality of the participants throughout the study. First, Institutional Review Board (IRB) approval was obtained prior to initiation of the study sampling procedures. Once approval was given in June 2011, the first participant was approached. Once he agreed to participate, full disclosure of the study's purpose was given, and the informed consent reviewed with the participant. The participant initialed each page of the consent indicating it had been reviewed and explained. Each participant and the researcher each signed and dated the back page of the consent form once any questions were asked and answered

(Appendix C). Participants were informed that their identities would be protected by use of pseudonyms and coding.

After each participant gave permission, he was offered a copy of the informed consent form, including contact information of the researcher and faculty advisor. Each subsequent potential participant was recruited in the same manner. Signed informed consent forms were kept in a locked file cabinet in a locked office at 720 Clydesdale Avenue, Seymour, Tennessee 37865-4940.

The researcher had the interviews transcribed by a professional transcriptionist, who saw only pseudonyms attached to each interview transcript. The transcriptionist was required to sign a confidentiality agreement prior to accessing the interview recordings to transcribe (Appendix F). These transcripts were kept in a locked file cabinet in a locked office to which only the researcher had access. This office was located at 720 Clydesdale Avenue, Seymour, Tennessee 37865-4940. Participants were made aware that participation is voluntary and they could withdraw at any time without penalty. No participants withdrew from this study once an informed consent was signed. Should a participant have decided to withdraw prior to study completion, any data collected would have been deleted from the digital recording device and transcripts destroyed by using a paper shredder. This data would have been excluded from NVivo 9 and any subsequent analysis.

Data Generation

Screening of participants began via telephone to determine whether inclusion criteria were met (Appendix G). The researcher also obtained demographic information and discussed interview location during this telephone call. Demographic information requested included age, marital status, county of residence, age of each child, and the specific intellectual disability of the

affected child. At the conclusion of this telephone call, the first six fathers were asked to bring an object to the interview if possible that reminds him of each child. This object, whether it was available at the interview or only described, assisted the participant in focusing on the corresponding child as well as to assist the researcher in understanding the meaning the object had for the father. Stake (1978) described the most effective means of adding to understanding in qualitative study is by using a technique that gives the reader a focus through an illustration. Using an object that the father chooses helped illustrate the father's relationship with the child being discussed throughout the initial interviews.

The first six participants did not bring an object to the interview that reminded them of each child but discussed those objects without difficulty. Some of these first six fathers described objects representative of activities each of their children liked doing, while others described a shape such as a heart or something to represent an attribute such as a firecracker. The researcher did not include this question in the latter two interviews as the previously interviewed fathers had had no difficulty in remaining focused on the child being discussed. The object also did not appear to have any particular illustrative importance to the participant's relationship with the child.

Once each participant was screened, additional data were gathered by semistructured personal interviews with participant fathers. Using birth order of the sibling dyads, the first portion of the interview focused on the older child and, after a break, the second part of the interview focused on the younger child regardless of which child had the intellectual disability.

Each interview was conducted in a quiet location mutually agreed upon by the participants and researcher. To ensure the privacy and confidentiality of the participants, but also to maintain the safety of the researcher, locations such as public libraries having private

rooms was suggested. Participants' homes were avoided to decrease distractions during the interviews for the participants.

Instrumentation

In a qualitative study the researcher serves as the research instrument by which the data are gathered, transcribed, analyzed, coded, and then inductively transformed into themes (Denzin & Lincoln, 2000). Obtaining qualitative data required "perceptual acuity in observation and [a] finely developed capacity for eliciting detail from respondents" (Barrett, 2007, p. 418). Given this need for detail, the researcher used both field notes and an observational journal to record researcher feelings and thought processes and to document study progress before and after interviews.

The researcher conducted one pilot interview with a volunteer father who had three children fitting all inclusion criteria with the exception of his children's' ages. This pilot interview was useful in giving the researcher experience in organization, pace, and interviewing techniques as well as to elicit any personal feelings arising from the interview discussion. The questions from the moderator guide were used to determine their utility; specifically their wording, the willingness of the participant to answer them, and the order in which they should be asked. In summary, the pilot interview assisted the researcher in fine tuning the interview questions prior to using them with the actual study participants.

Field Notes

To add to the robustness of the data collected, the researcher recorded interpretations of participant behaviors, facial expressions, nonverbal cues, and perceived attitudes after the conclusion of each interview. Few notes were taken during the interview to increase the rapport with the participant. As each transcribed page was numbered, both by page and line by line, the

researcher attached the journal entries to the corresponding interview section by line number. With Smartpen technology it was possible to record the interview and jot short notes onto Livescribe™ dot paper such as the time or an emotion to coincide with the portion of the interview. This technology also allowed transference of these notes directly onto the computer enabling them to be easily transcribed and then added to the data in NVivo 9. According to the Livescribe™ Website, the program allows the individual to:

- Save, search, and play back notes and recordings on your computer,
- Search your handwritten notes for keywords,
- Organize and manage your notes,
- Export your notes and audio, and
- Upload notes and audio to your Livescribe account (Livescribe, 2011, para 1).

In this way it was possible for the researcher to reflect on the nonverbal cues and personal perceptions that occurred during the interviews to inform the analysis and subsequent results.

Reflective Journal

It is imperative to begin entries in a reflective journal immediately after each interview with the participant fathers. The researcher used these reflections to record personal feelings, expectations, impressions, or thoughts held prior to the interviews, the context of the interview, as well as any personal feelings elicited by the interviews. This journal was also used to record the inductive thinking process undertaken by the researcher after each interview. These too became part of the data and subsequent transcript using Smartpen technology to attach the notes to the particular interview section to which they apply.

Interview Guiding Questions

Although these interviews were semistructured to allow each father's personal expectations and experiences to surface, questions have been developed to guide each interview. Interview questions were intended to guide the initial stages of the dialogue. As semistructured interviews garner more thoughts and feelings from the participants, the researcher asked open-ended questions and remained flexible in regard to the direction the interviews took (Wood & Ross-Kerr, 2011). The guiding questions for each portion of the interview were:

- "Tell me about your experiences of being _____'s father?"
- What did you see as your role in _____'s upbringing?"
- "Tell me about what it's like being _____'s father."
- "Can you tell me what activities _____ enjoys doing?"
- What is _____ good at?"
- "As a father, what role do you think you have in helping _____ reach his or her highest level of functioning?"
- "Tell me your experiences with getting the information you need about caring for _____."
- "Can you tell me about the object you brought that reminds you of _____."
- If the participant did not bring an object, "Can you tell me about an object that reminds you of _____?" "Can you tell me in one word why you chose this?" "What does it mean to him or her?"The researcher will request additional information by asking the participant, "Can you tell me more about that" (Appendix H)?

Once the interview progressed from the initial interview question, the researcher asked supplementary questions eliciting further details when necessary. Then the interview continued through each guiding question if appropriate to express the thoughts and experiences of the participants until neither the participant nor the researcher had any further need to continue.

Each interview was recorded on a two digital voice recorders to maximize the accuracy of the data obtained and decrease the likelihood of technology failure. Once each interview was complete, the researcher gave the digital audio recordings to a professional transcriptionist for transcribing. After signing a confidentiality agreement, the transcriptionist used Microsoft Word and foot pedals to transcribe each interview directly from the digital voice recording. Each transcribed interview was numbered line by line and page by page for ease of reference. This format also enabled the researcher to attach the field notes and reflective journal entries from the Smartpen recording to the particular interview section. These transcripts were then read and listened to at least once simultaneously and then repeatedly read prior to the next interview to allow for active engagement with the data.

Data Management

Once transcription of each interview was complete, ongoing analysis continued throughout data collection. First the researcher used colored highlighters to color code the transcripts according to themes as they emerge from the data. To further organize and reduce the data into meaningful classifications, the researcher then entered the data into NVivo 9 for coding and sorting.

Rigor

Morse, Barrett, Mayan, Olsen, and Spiers (2002) stated, “Without rigor, research is worthless, becomes fiction, and loses its utility” (p. 14). Rigor in qualitative inquiry includes

credibility, auditability, applicability, and confirmability (Appleton, 1995; Guba & Lincoln, 1981; Russell, 1999; Sandelowski, 1986). Miles and Huberman (1994) add objectivity, reliability and dependability, internal validity, authenticity, external validity, transferability, and fittingness as descriptors of quality, and group similar concepts together. Rigor in a qualitative study also includes the ability to be transparent inasmuch as the researcher is able to explain both to the participants and to others exactly how the research was conducted (Wood & Ross-Kerr, 2011). Sampling must also continue by actively seeking participants until the researcher has abundant information about the expectations each participant had about becoming a father and how those expectations compare to the reality he is currently experiencing. Once the data obtained from later participants became redundant during the current study, the researcher stopped seeking additional participants.

Objectivity and Confirmability

Verification at each step of the research process was completed to ensure methodological congruence and the identification and correction of errors prior to moving to the next step (Morse, Barrett, Mayan, Olsen, & Spiers, 2002). By ensuring congruence, the resulting conclusions are more likely to be based on data rather than researcher assumptions and biases (Guba & Lincoln, 1981). In addition, any personal biases or assumptions encountered were explicitly considered before moving forward with the study. To do this, the researcher used field notes to record thoughts and feelings immediate following each interview, transcribed them to include as data, and then reflected on these prior to the next interview.

Reliability or Dependability and Auditability

To establish reliability the research questions were verbalized as clearly and concisely as possible to avoid participant confusion. The researcher avoided slang or ambiguous wording,

and consistently posed relevant questions in a thoughtful manner (Rew, Bechtel, & Sapp, 1993). Field notes and a reflective journal were kept by the researcher to also assist in establishing study reliability and auditability. These notes and other research records comprised the audit trail and are a "transparent description of the research steps taken from the start of a research project to the development and reporting of findings" (Cohen & Crabtree, 2006, para. 1). These records include raw data, personal notes, categories, themes, and the connections between them (Halpern, 1983; Rodgers & Cowles, 1993). These notes and other records for the audit trail were also kept in a locked file cabinet in a locked office at 720 Clydesdale Avenue, Seymour, Tennessee 37865-4940.

Internal Validity or Credibility and Authenticity

Lincoln and Guba (1985) describe two different components of establishing credibility: Conducting a research study in a way that increases the trustworthiness of the results and portraying this trustworthiness to both participants and readers. In the current study the informed consent document was described in detail including the purpose of the study and the methods by which it will be completed (Appendix C). Digital voice recording assisted in establishing credibility as the recordings ensure verbatim transcription. The researcher also continued to interview participants until data saturation was reached to ensure thick description of the fathers' expectations and experiences. Data saturation was reached when the expectations and experiences discussed by the fathers became redundant and no new information was obtained. This process ensured thick description by ensuring all new data obtained from the fathers' stories were included. To further increase study credibility, the researcher used active listening during interviews, minimized distractions, avoided writing lengthy notes until after the interview was completed, and showed genuine interest in the discussion (Rew, Bechtel, & Sapp, 1999). Trust

and rapport were critical to the credibility of the researcher as the study instrument and to the study results. Finally, the researcher used multiple meetings and email discussions with committee members to explore other interpretations of the data and to identify the existence of researcher biases. These six meetings were imperative in this process as a method to spur the researcher's thinking to consider other possibilities and to ensure faithfulness to the study design. It is through this method that the researcher explored other possible themes not readily apparent.

External Validity or Transferability and Fittingness

Transferability is the "extent to which findings can be transferred to other settings or groups... [and is] analogous to generalizability" in the quantitative paradigm (Polit & Beck, 2004, p. 734). The transferability of study results depends in large part on the amount of contextual information provided by the researcher and the continuation of sampling until participant stories become redundant (Polit & Beck, 2004). The researcher described the methods in sufficient detail to allow readers to determine if the results "fit" other individuals meeting the exclusion and inclusion criteria to make comparisons in similar contexts (Polit & Beck, 2004).

Applicability

If the aforementioned quality measures were met, the results of this study can be used by nurses to better anticipate the needs of men in their roles as fathers of children with differing intellectual capacities. Applicability is judged by how each aspect of the research project, such as the setting and participants, are comparable to the setting and participants of interest for another project. It is only through thorough explanation of each aspect that applicability can be judged. Therefore, the researcher ensured explicit descriptions at each stage.

Data Analysis

Data analysis through qualitative content analysis begins with the first data obtained and continues concurrently until data collection is complete (Miles & Huberman, 1994). Corbin and Strauss (2008) stated, "Being immersed in data analysis during data collection provides a sense of direction, promotes greater sensitivity to data, and enables the researcher to redirect and revise interview questions or observations as he or she proceeds" (p. 58). It is through complete data immersion that insights into the data can "spring forth" (Elo & Kyngas, 2007, p. 109). Therefore, each interview was transcribed prior to the next interview to allow for inductive reflection on each interview separately, and then for reflection on how the previous interview should inform the next. Once each interview was complete and transcribed, the data were entered into the qualitative data management software program NVivo 9. This program was used to help organize and code the data, including the field and reflective journals, into mutually exclusive categories or nodes. According to Sandelowski (2001), this is "integral to the analysis process, especially to the recognition of patterns in data and deviations from those patterns..." (p. 231). Initial data organization and coding was based on the moderator guide for semistructured interviews. If these were applicable to the data obtained, the researcher continued using this organizational method. Otherwise, the researcher continued to organize the data based on patterns evident after coding. Finally, the researcher completed the content analysis process by using the patterns present in the data as they were organized (Wood & Ross-Kerr, 2011) and abstracting them further to encompass those patterns into applicable themes (Elo & Kyngas, 2007).

Summary

Interviews with fathers in and around Knox County, Tennessee meeting inclusion and exclusion criteria was completed by asking them about their experiences of fatherhood with their children both with and without intellectual disabilities. Little is known about this experience, making a descriptive qualitative design appropriate. Once each interview was complete, the digital recording was transcribed. The transcribed interview was then analyzed prior to the next interview to determine if changes to the forthcoming interview plan should be made. Measures such as an audit trail and meetings with committee members assisted in achieving quality results. With the assistance of NVivo 9, data management and analysis were completed, resulting in themes.

CHAPTER 4

RESULTS

Experience is not what happens to a man. It is what a man does with what happens to him.

-- Aldous Leonard Huxley, *Texts and Pretexts*, 1932

Introduction

The investigator used qualitative description to explore the expectations and experiences of eight fathers raising children both with and without intellectual disabilities. After each interview was coded using the research questions and moderator guide as a foundation, ongoing analysis of the participant transcripts consisted of categorizing the data into patterns, then finally abstracting patterns into themes best representative of the meaning derived from the data. Four main themes emerged from this iterative process.

Fathers Raising Children with Differing Intellectual Abilities

Babies do not come with instruction manuals. Expectant fathers may read books, access Internet sites, or discuss having children with other fathers as a way to prepare for the experience, but nothing compares with reality. Just as each child is unique, so too are the experiences each father lives through in raising each of his children. It is this uniqueness of experiences that creates a joyful, intense, and frustrating journey, full of possibilities.

When fathers' unique experiences include raising children with differing intellectual abilities, the interactions between fathers and children require flexibility and overall sensitivity to the needs of children. Repeated, hands-on contact is the best facilitator of experience and finesse. Hands-on contact requires active engagement in the daily care activities required to raise children. Experience is the only way fathers will learn about their children's personalities,

and areas of ability or difficulty. Although most fathers can use mainstream advice to teach typically developing children, those who have children with intellectual disabilities must design each intervention or interaction to fit each child's specific needs (National Dissemination Center for Children with Disabilities [NICHCY], 2012). Fathers in the study assumed active roles in their children's daily lives, although all but one father worked full time.

Learning is a natural occurrence for a child, taking place long before the beginning of formal education. For children with expected intellectual abilities, learning occurs as children explore and interact with the environment. Although each child may be more adept at one or more subjects, no special arrangements are usually required for general education. For those diagnosed with an intellectual disability, however, federal law mandates the provision of early intervention services during the infant and toddler years via an Individualized Family Services Plan (IFSP). Once children reach preschool age until age 21, the law stipulates that children must be integrated into the general education curriculum but with an Individualized Education Program (IEP) (NICHCY, 2012). This IEP specifies the assistance and support needed to meet special education, therapies, and overall educational needs of each child (NICHCY, 2012). The assistance and support can be "supplementary aids and services" (IDEA), adaptive skills needed for daily life, and transition planning to specify plans for when children reach adulthood (NICHCY, 2012). Children with intellectual disabilities must have both IFSPs and IEPs in place, requiring many meetings with school administrators, therapists, and parents over the years until children reach the age of 21 years. Proponents of equality for those with intellectual disabilities believe, although the law provides for these programs, it is parents who must "be fierce" in demanding the services children require (Burns, 2012). All parents must advocate for their children, but advocating for children with intellectual disabilities requires additional effort.

Preparing for the future is an essential parental task fathers do for their children. Fathers protect, lead, advise, and guide their children, facilitating the growth of children into successful adults. However, for those parenting children with intellectual disabilities, this role is even more complex. For children with profound intellectual disabilities, fathers, with mothers if involved, must decide to whom care responsibilities will fall after the parent or parents can no longer function in the capacity due to illness, injury, or death. Is it fair to ask typically developing siblings to take on the responsibility? Should children live in a group home, be placed in state custody, or remain with a relative? Complex legal and ethical issues must be considered when raising children with intellectual disabilities that do not arise with typically developing children. Although advocates advise to start planning for the future as early as possible, preferably from the start, this can be difficult when coping with the physical and emotional demands of raising children, much less the daily barrage of physician appointments, meetings, therapy sessions, and health-related bills so common with special needs children. Some fathers participating in the study had already made these plans, whether formally written or only orally. As with any decision affecting a family, the right one is the one best for all affected by it (Reilly, Huws, Hastings, & Vaughn, 2010; Stabile & Allin, 2012). To provide a closer look at the participants, a description follows accompanied by specifics on how each was enrolled in the study.

Demographic Descriptives

The eight participants ranged in age from 25 to 57 years with a mean age of 41.25 years and a range of 32 years. Six of the eight completed some college or technical training, one attended school through the 9th grade, and one graduated from high school. One participant was of Hispanic, Puerto Rican descent and the remainder non-Hispanic, Caucasian. Six of the eight lived in East Tennessee, one in Middle Tennessee, and one in West Tennessee at the time of the

interviews. One of the participants had two children affected by intellectual disability and one unaffected, whereas the other seven had only one child affected among their normally developing children.

Participant Interviews

Interviews were conducted from mid-August 2011 through early April 2012, and ranged from 56 minutes to 178 minutes in duration. Participant recruitment was through research study flyers and word-of-mouth, assisted by three regional or state-wide agencies: Tennessee Disability Coalition, East Tennessee Technology Access Center, and Support and Training for Exceptional Parents in Tennessee. Six of the eight participants used electronic mail (email) to express interest in participating. Only one potential participant declined once he received the informed consent information from the investigator. During the initial telephone or email contact, each participant was screened to ensure he met the inclusion and exclusion criteria. Once these criteria were met, the investigator suggested a public venue in the participant's area with private meeting rooms in which to conduct the interview. The day before the interview was to take place, each participant received a reminder telephone call or email to ensure the interview time and location were still convenient. None requested to reschedule and each interview took place as arranged.

Prior to starting the digital recording, each participant was given the opportunity to ask questions about the informed consent document or interview procedures. They were also given the opportunity to withdraw from the study. Each participant was asked to begin by giving a description of each child, including age, gender, and the specific intellectual disability diagnosed in the affected child. Then each child was discussed, beginning with the oldest first, regardless of which child had the disability.

Participants- Who Were They?

Table 1 contains a summary of participant demographics. P-A was a 42 year-old father of two boys, ages 12 and 10. He was married to his children's mother and worked in an industrial plant. The 10 year-old son was the child with the intellectual disability.

P-B was a 48 year-old professional with three male children, two of which (oldest and youngest) were biological. The eldest child was 16, the middle child 13, and the youngest, affected child was 10 at the time of the interview. He was married to the two younger children's mother.

P-C was a 45 year-old working professional with three children. He was married to his children's mother; His oldest son was 16, the middle affected son was 14, and his daughter was 10.

P-D was 31 and married to the mother of his three children. He was a small business owner and both of the oldest children who were males were affected by an intellectual disability. They were 12 and 9 at the time of the interview. His youngest, a daughter who was 5, was developing as expected.

P-E was a working 43 year-old who, with his wife, had four children. The older two were girls, aged 11 and 9, and the younger two boys, aged 7 and 3. The older male was the affected child.

P-F was a married 57 year-old who was employed with two adult biological children. Along with raising their own children, he and his wife adopted seven others, two of which were still living in their home. In addition, they fostered children while the biological children were still living at home. The elder of the two adopted children still living at home, a boy, was the

affected child. One adopted daughter died just prior to turning 4; she was also affected by a global intellectual disability.

P-G was an employed, married 39 year-old with four children-- three boys and one girl, ages 9, 7, 3, and 18 months, respectively. The youngest son was affected by an intellectual disability.

P-H was a married, 25 year-old stay-at-home father, with one biological son and four step-sons. The boys were 16, 11, 9, 8, and 3, with the youngest being the biological and affected child.

Table 1

Participant Demographic Summary

Participant	Age	Marital Status	Affected Child's Gender	Affected Child's Diagnosis	Physical Anomalies Present	# Other Children	Gender Other Children
P-A	42	M	♂	Asperger's syndrome	No	1	♂
P-B	48	M	♂	Autism	No	2	♂♂
P-C	45	M	♂	Austism	No	2	♂
P-D	31	M	♂♂	Autism	No	1	♀
P-E	43	M	♂	2 rare genetic disorders*	Yes	3	♀♀
P-F	57	M	♂	Fetal alcohol syndrome	No	2 biological 5 adopted (1 died)	♂♂ ♂♂ ♀♀♀
P-G	39	M	♂	Down syndrome	Yes	3	♂♂♀
P-H	25	M	♂	Idic 15	Yes	4	♂♂ ♂♂

M = married

*Not included to protect the privacy and confidentiality of the participant

Thematic Findings

It is much easier to become a father than be one.

-- Kent Nerburn, *Letters to My Son: Reflections on Becoming a Man*

Completion of data analysis from the eight interview transcripts generated four main themes: 1) *Learning to Dance in the Rain*, 2) *Just Do What Needs Doing*, 3) *The Power of Patience*, and 4) *Nurturing Uniqueness*. These main themes yielded subthemes to further explicate the fathers' experiences. Quotations from the fathers' interviews exemplify these themes and subthemes as each is discussed.

Throughout the majority of the eight interviews, each participant described his expectations prior to the births of his first children. All but one wanted at least one child, and one father wanted as many as six. They expected to father at least as well as if not better than their own fathers had. As their children were born, most expressed how they began incorporating the new routine of caring for each baby into their daily responsibilities of providing for the family. For all but one father, the first born children were of typical intelligence. For the participant whose firstborn was affected by an intellectual disability, it was not immediately apparent. Two of the eight fathers knew before the affected child's birth that a problem existed based on an ultrasound evaluation and other testing.

Upon learning of the intellectual disability, each father described the experience differently. P-A described a sadness for his child as well as a sadness for himself. He also stated there was continual heartache and some anger in knowing there had to be a new set of rules for his affected child. P-B did not verbalize his reaction at his third child's diagnosis, but researched it a great deal to understand it better. However, he did describe the shock in hindsight when

comparing both himself and his firstborn to the affected child. He elaborated by stating that while they were researching their son's disability, he and his wife both recognized himself in the descriptions they read. P-C believed the possibility of his child having an intellectual disability was "hokey" and described one particular event that made a believer of him. P-D expressed his feelings by stating, "It just took my life away" when his firstborn was diagnosed.

P-E had a different perspective than other participants because of the overwhelming anomalies with which his third child was diagnosed prior to birth. He and his wife were told a "what he-would-not list" and that he most likely would die before birth or shortly thereafter. If he were to survive, the "would not list" included milestones such as walking, talking, and eating normally. He elaborated by saying this entire period was "extremely difficult" and in some ways it would have been easier if the fetus had died before birth "knowing that he would just die anyway". He described himself as "overjoyed because your son lived...but still apprehensive because he could die at any time".

P-F knew he was adopting children with behavioral or intellectual problems prior to bringing them into his home. However, one adopted child was found to have an intellectual disability instead of a behavioral disorder, and this participant verbalized frustration at being misled by those facilitating the adoption. P-G described discovering the presence of an intellectual disability just after his third child's birth was quite a shock and spoke of the uncertainty of this child's future. He further described himself during that time as being sad. P-H stated he knew before his wife got pregnant with his first biological child he "was going to have a child with problems" and was concerned after birth with the newborn's lack of interaction and failure to latch during breastfeeding.

Learning to Dance in the Rain

Once most of these fathers had some time and were able to process the information regarding their children's disabilities, most shifted perspective. The sadness and feelings that the world was coming to an end dissipated to feelings of thankfulness for the child they had been given. They began seeing the positive aspects of their children and remained focused on those.

You know, and then they're all playing football, and my kid can't do that, you know, but it could be worse, you know. They could be in a wheelchair for the rest of their lives or they could be closed off to the world and never speak to me. At least my kids will come in here and have a conversation and say 'hey, Dad, I love you'... If you focus on the negative part it will overcome you and you can't enjoy life. It was kind of easier when we found out {second child's name} was autistic because we knew what we were in for... we knew it wasn't the end of the world... (P-D)

The situation we were put in we were never... we were never thinking he was ever going to be anything but what he is... what he is, is our highest hopes. I guess I'm...I'm...you gotta play the card your dealt with, and if you dwell on what might have been... ..what could have been, what you wanted...it's just not going to be that way, so enjoy what you've got, you know, I guess would be the thing I would say. (P-E)

She had that smile, and the thing about [child's name] was you never had a bad enough day that was worse than hers. Your worse day was never even close to her best. (P-F)

We've seen even in three years, we came from being in distress for what he's going to be to, you know, I don't think our lives would have been as full with the...if he wasn't in our lives. He has definitely changed a lot of our thoughts about how the world works and how life works, including he has put in perspective 'us,' you know. (P-G)

Fathers described learning to enjoy life despite living with unexpected difficulties on a daily basis. The researcher identified two subthemes from the main theme of *Learning to Dance in the Rain: The Future is Always Unknown* and *Expectations Don't Change*.

The future is always unknown. Following the realization that dwelling on the negative aspects of raising children with disabilities was not healthy or productive, participants validated their enjoyment of life by looking toward the future without expectations. Obviously the future for everyone is always unknown. In this way fathers could spare themselves disappointment if their children did not meet some developmental target and continued to focus on future possibilities.

You know, the thing with [child's name] is they don't know. You know, like a Down's (sic) syndrome kid you have these things that you expect. So I have no expectations about him [speaking about his son with multiple problems who according to his physicians at birth should not have survived]. (P-E)

He's, you know, the big question mark. You know we don't know what he's going to be, and we just got into the mindset that you have...these...all these things were just sort of like this. You want things to happen, and it just didn't happen that way with [child's name]. (P-G)

One participant used a decision-making tool to assist him in determining the best path for his children and their future. He described his belief that each decision should be made knowing he would not be given another chance in the future to correct a mistake.

Treat your kids like it's your second chance because you'll never get another chance to raise your children. (P-H)

Expectations don't change. When these fathers discussed their roles in raising their children, they did not describe any differences between their expectations for any of their children or for themselves as fathers. They expected to raise children who would be independent and responsible as their particular abilities allowed. Children were expected to act appropriately, know right from wrong, and push their potential to the limit. When lapses occurred, so did consequences, regardless of intellectual ability.

Don't sell yourself short. You can do so much more. Don't feel like, 'well, this is me and this is how it is'... I want him to learn as a kid not to be so held back or afraid... My approach is to treat them both the same. (P-A)

I'm gonna push this child, and I'm going to try to make them, help them be the best they can be. Have them try to work at getting better. (P-C)

You know, one thing I put in my mind is I will not treat them any different. I'm not going to say well he can be bad, he can act up. It's okay. He's autistic. I said that from day one. You know, I will teach my kids right from wrong... Need to give them values, respect, and to help people when you can... I want them to know what struggle is, but never want them to experience it. (P-D)

You do the right thing, and if you don't do it you have consequences. Now, your consequences may not be as severe as the other ones who better understand... You don't lower what you do. I mean, it's his just like, I still expect you to behave. You do what you're told to do... you know. Because you have this disability, does that make it okay? No. (P-F)

I don't...I don't think I'm going to have a mentality of 'this is what I want to have him settle for'. I'm always going to want him to try to be, you know, the best of what he wants to be...in any type situation, and that's with all the kids... I don't try to push them towards a specific, you know, skill set. You know, you should do the best of what you can...with what you have. [Child's name] is not separate or there's nothing different in his life that's different in the other three. (P-G)

Just Do What Needs Doing

Regardless of which child was born with the intellectual disability, the first, the last, or in between, fathers repeatedly described on-the-job training. Although all but one father worked outside the home, each spent quality time doing whatever needed to be done. Sometimes they had no choice in the decision because mothers were away from home working or at school, or had left the family home.

With the birth of their first child, these fathers described jumping in and doing whatever needed to be done for the household; some described how they felt prepared for child rearing and were surprised to find how difficult it was at first. Others had experience, either as older siblings assisting in providing care for their younger siblings, or from repeated exposure to other children through day cares or babysitting. Regardless of their preparation for fatherhood, with children developing as expected or diagnosed or born with intellectual disabilities, they described the experience in diverse ways.

P-B became a single father when his wife left him. He got up in the morning, took his child to school, and went to work during school hours. Once the school day ended, he spent the afternoons and evenings with his child until bedtime when a babysitter arrived, then he went back to work sometimes until in the early hours of the morning. He would sleep a few short hours, then get up and repeat the schedule.

The day-in, day-out was a bit of a shock... And to a large extent what you learn and learn quickly is that you just do it one day at a time...and, you know, that's all you can do. And, you know, there doesn't end up being a lot of planning to things..., it's just 'okay, got through today, got through tonight'. (P-B)

It's not like I'm just 'okay, I've learned all...I mastered it all', and you know, it's

still tough, you know, but it's one day at a time. And not everything is perfect, and um, you've got to adapt, you know. That's the main thing is just to adapt and overcome it, you know. You've gotta fight. You can't say my kid's autistic, you know, he's never gonna be nothing or she's never gonna be nothing. (P-D)

...you kind of learn as you go, at least with the first one, what your boundaries are going to be. What you find acceptable. What you find not acceptable. You've gotta do it. There wasn't really any [plan] with [affected child]...I mean in some ways you're overjoyed because your son lived, you know, you weren't expecting it to happen. That first year [after the affected child was born] was probably the hardest of my life... because of the pure time it took. ...it's different than the "your son's gonna die...oh he lived, and he's completely normal"... [it's] "your son's gonna die...hey, he lived, and he's not normal" you know, so I mean [my wife] and I looked at him last night and said 'I can't believe he's this old'. (P-E)

But you really learn quickly that they are the ones going to be teaching you or showing you what life's about than anything that you can ever show, you know, whatever... (P-G)

At first it felt like I was [just] in the father role. I had to do the fatherly things, make the fatherly decisions... You know, I have to be responsible and treat them like they're my kids... I really didn't know...I knew how to babysit kids, but I didn't know really how to raise kids. [after becoming stepfather to four children and before his biological child was born]. (P-H)

The Power of Patience

During the interviews, some participants used the word "patience" to describe their experiences of raising their children and how they survive the daily "dramas and traumas" (P-B).

Their survival required patience.

Patience and one day at a time. Me and my wife are like 'well, you know, they can do it. You know. We just gotta do it slower'. You can't just throw them in it and let them go. We just started when they were really young working with them, because I said I wasn't going to have a kid that couldn't do for himself. I don't care if he's autistic or what it is. You know, I want them to be able to do for [themselves]...and they can. They can do anything. It just might take them

longer to learn it and longer to program it into their brain to where it becomes an everyday thing, so we just stayed on them, you know. (P-D)

You know, it's just the way it is, and you know, you still have to teach them. They can still learn. Just gotta have more patience, you know, the whole patience thing. You gotta have more patience. It's gonna take longer. They can still do it. (P-E)

You have to have a lot more patience with [affected child's name]. We...constantly ...he's obviously more hands on. (P-G)

You have to have patience, because if you don't you'll end up killing yourself... or someone else. (P-H)

A subtheme inductively derived from this main theme of *The Power of Patience* was *Keep Moving Forward*. It was this patience that made each child's progression possible.

Keep moving forward. Participants described setting goals for each of their children, especially the ones with intellectual disabilities. Each step was crucial in supporting each child's development.

My idea on ultimate goals was very narrow. My thought was that if you can teach them to read and to enjoy reading then they can learn whatever else they need, and they'll be fine in life. So from the youngest age with all of them I read to them every night... (P-B)

Set goals, but small goals. You know, don't expect them to keep up with everybody, but help them where they can... You know, it's not the end of the world, and you know, don't set the goals too small and don't set them too high, but do have goals. (P-D)

...It was mainly my goal was when they were 18 they should be able to live out in the world or at least have the tools to do that. (P-E)

I try to keep them...I have a term that I use at work. It's 'keep moving forward.' Always, constantly keep something, you know, don't be one hundred percent satisfied with just being finished. Go ahead and, you know, if you've got something accomplished that's a wonderful thing, but don't think that once you're done with that that you're done. That you keep, you know, move on to the next accomplishment... that to kind of strive to be, you know, I try to emphasize to them to strive to do very well. (P-G)

Sometimes the goals were not for the child. One participant grew up watching his mother being abused and being abused himself. His father worked long hours and did not play an active role in his children's lives. After leaving his home state and moving to Tennessee with his father's side of the family, he survived by eating whatever he and his siblings could find from dumpsters. He was exposed to drugs and alcohol use among family members during this time and began using both himself at the age of 12. After getting married and having his first child, he was incarcerated.

...Then it took me awhile to wake up, and it actually took me being incarcerated... to see where I was going and the example I was setting for my son.... I've done a lot and seen a lot that I don't ever want my kids to do or go through or see. I never want them to experience being hungry... I'm glad I went through all that because, you know, I can survive anywhere. I know I can do a lot, and I never... I want my kids to know where I come from and I want them to know what struggle is, but I don't ever want them to experience it. (P-D)

One father's adopted child had multiple disabilities and was frequently hospitalized. He worked on his own disposition using his affected child's smile as his measuring stick.

She had that smile, and the thing about [child's name] was you never had a bad enough day that was worse than hers. Your worse day was never even close to her best. You came home and you're going 'I'm unhappy why?' (P-F)

Nurturing Uniqueness

Every child is different regardless of intellectual abilities. Although the expectations for acceptable behavior, holding up familial values, and respecting yourself and others do not change, other aspects of raising each child must be altered and specifically chosen for the particular child.

It was his way, not my way [during a family trip when the affected child would not respond to his father and refused to comply regardless of any threatened consequences]. (P-C)

Yeah, people asked what [he] has, and we're like [child's name] syndrome. That's what [my wife] calls it... With [child's name] it's like I really just have no clue, and...um...and some kind of throw up their hands and say 'I don't know', where others just treat him as [child's name]. [Discussing how people treat his child] (P-E)

The child is gonna be the child. It takes a special type of family to take care of them. They're going...you've got...it's going to be a lot of work, but the reward out of it is unbelievable. They're...these children are the most precious thing that will ever be in your life. (P-G)

Help them find their own path. The experience of these fathers finding ways to use their children's uniqueness to help their children grow was evident. Children are unique individuals. They may have similarities in physical, intellectual, and psychological characteristics, but no two are exactly the same. Papalia, Olds, and Feldman (2008) found this to be true even with twins raised together. The fathers in this study expressed their responsibility for guiding their children toward becoming the individual they are capable of being, without forcing them to follow others' paths.

...I get frustrated sometimes with [first child's name] lackadaisical personality... and I'm not trying to make him like me, but I want him to... you know, but to me there is nothing wrong with having a good drive. Have a purpose... but there is that little bit more than just getting by. [With affected son's name] we were trying to intervene [so we] kept subjecting him to normal life... and we would try to calm him down in that environment and just keep saying 'It's ok' and just reassuring him that it seems weird but it's ok. (P-A)

I am going to try to make them, help them be the best they can be. You need to find their path and use their abilities to create that path. It's how you create the paths and deal with all three of them as individuals. Never pigeon-hole your kids. Never tell them they can't do something. And always help kids to do, even if they don't think they can do it, help them to do what they think they can't do. Help them achieve and do whatever you can to help them achieve. (P-C)

The only surprises we get is when they do something we didn't think they could...It'd be easier if their autism was the same, but I never met two autistic kids that were the same. (P-D)

The first born child of P-G and his wife was always small for his age, and after testing was completed, he was found to lack sufficient growth hormone.

[We] just determined that God had decided him to be a shorter fellow, so that's what he's going to be. We didn't want to go through daily shots until he was 18. [For all my children], you know, make sure that they just basically learn how to...to...I mean, I guess be successful. [To] learn from their mistakes, which I let them make their mistakes. I don't...I don't try to coddle them too much. I don't try to push them towards a specific, you know, skill set. You know, you should do the best of what you can...with what you have. [About his child with the intellectual disability] I'm always going to want him to try to be, you know, the best of what he wants to be... (P-G)

Ability-specific learning. Individual learning styles vary significantly with children of normal intellectual abilities. Individuals may receive, process, and retain information more readily seeing the topic in action, hearing details about it, using their hands to experience it

themselves, or a combination of these (Felder, 2012). As individuals with intellectual disabilities have deficits in the processing of received information, the deficit only adds to the puzzle of how best to present the information so children can learn. Participants discussed the experience of teaching their children both with and without intellectual disabilities using each child's uniqueness to guide them.

It's a question of the one who succeeds is the one who realizes and understands there is something different about themselves and have learned how to adapt and deal with normal situations and move forward... [Once the child's teacher knew the diagnosis]. Once you understand how to deal with him you can deal with him normally in a way he understands. It's just changing your approach. (P-A)

There is a talk about people saying not to try to have favorites or not to play favorites, but each child is unique in the way they are going to grow and the way they'll learn, and the way they are going to learn things, and the trick is probably trying to find out what is the proper path for the one child that's moving fast, the one child who is moving slow, and the one child that needs more assistance (P-C)

You have to be open-minded about it, you know. You have to learn ways that's easier for them to learn. You've got to do what's best for them. If you can find a way whether it be a TV show that helps them learn or a set of cards or, you know, whatever. You know, you've gotta do it. You know, you've got to. (P-D)

So, we don't expect him to...he's been working with eating and stuff, but he just wants nothing to do with it. He's got that aversion or whatever you call it. There's a chance if we didn't have [the names of the first two children] that he might be eating because we could have just spent so much more time with him. (P-E)

You know, so that he learned, but he didn't necessarily learn everything that everybody else would learn. He learned what he needed to, to progress... (P-F)

I don't think we've changed our style. I mean if [child's name] gonna...we let him learn. If he hobbles himself up underneath a desk or what not we tell him, you know, you don't need to be there. He stands up and bumps his head, you

know. He's definitely learning at a slower pace. He's still...like I said...when it comes to figuring things out.....give him an opportunity, and he can figure things out. (P-G)

Summary

The researcher inductively derived the themes to facilitate description of eight fathers' expectations and experiences raising their children with and without intellectual disabilities. The main themes were: 1) *Learning to Dance in the Rain*, 2) *Just Do What Needs Doing*, 3) *The Power of Patience*, and 4) *Nurturing Uniqueness*. The theme *Learning to Dance in the Rain* expresses the joy these fathers found despite, or even because of, the intellectual disabilities present in one or more of their children. *Do What Needs Doing* represents the fathers' experiences of working diligently at care giving, household responsibilities, and other essential tasks. *The Power of Patience* theme depicts fathers working patiently to determine how best to raise all their children, furthering their development and abilities. The final theme of *Nurturing Uniqueness* expresses the unique qualities these fathers are finding among their children regardless of intellectual abilities and how they are adapting their fathering skill to each of their children.

CHAPTER 5

DISCUSSION AND IMPLICATIONS

A father is someone that holds your hand at the fair makes sure you do what your mother says holds back your hair when you are sick brushes that hair when it is tangled because mother is too busy lets you eat ice cream for breakfast but only when mother is away he walks you down the aisle and tells you everything's gonna be ok

— Unknown

Summary of Findings and Discussion

The purpose of this study was to describe the expectations and experiences of fathers who have parented children both with and without intellectual disabilities. Eight fathers participated in one-on-one semistructured interviews over an 8-month period; the unique characteristics of this sample are briefly highlighted. This chapter is a summary and discussion of study findings as they are integrated with applicable theoretical background and other existing literature. Practical implications for nursing practice, education, and further research related to the experiences communicated by these fathers are also discussed to inform nurses, educators, and researchers of these findings. Strengths and limitations of the study are also considered.

Unique Children, Unique Fathers

Study participants who agreed to be interviewed openly discussed their experiences of raising their children with differing levels of intelligence. One study theme highlighted these fathers' efforts to nurture each child's unique talents and abilities. There were unique characteristics among these participants that should also be highlighted.

In this study, these eight participants ranged in age from 25 to 57 years. This range of 32 years is significant as it portrays fathers at multiple stages in the fatherhood journey. Participants had been divorced and remarried, were single fathers for a period of time, and even remained married throughout births, adoptions, and fostering many children, some with devastating

intellectual and physical disabilities. This too is unusual as frequently discussed in the literature in this area; at one time it was more common for fathers to abandon children diagnosed with disabilities than to become completely engaged in raising them (MacDonald & Hastings, 2010). Finally, one participant had been incarcerated for a few months, and it was this incarceration that served as his "wake-up call" to behave more befitting a father. This uniqueness in these fathers may have contributed to study results and the implications thereof.

Learning to Dance in the Rain

The theme *Learning to Dance in the Rain* was originally conceived from work attributed to Vivian Greene, "Life isn't about waiting for the storm to pass... it's about learning to dance in the rain". It is the epitome of enjoying life despite the challenges that often accompany it. It characterizes participants' change in perspective as they assimilated their children's disabilities into their daily lives.

Fathers described their experiences of learning at least one of their children had an intellectual disability. This experience caused them sadness and feeling their lives were ending. Once these fathers had opportunities to digest the news and get to know their children, these feelings dissipated, becoming more joyful and present-focused. Some even expressed gratitude for being allowed to parent their extraordinary children, attributing them as gifts from God. Although the time it took to assimilate the effects of the disabilities into daily life varied widely, the "what-ifs" (P-A) were no longer at the forefront of their lives.

Brown (2009), in his memoir *Boy in the Moon: A Father's Journey to Understand his Extraordinary Son*, described the process of coming to this realization of enjoying the present moment with his son who was profoundly disabled: "Walker makes me live here and now; he leaves me no choice (p. 263)... I was already as close as I could be to him; there was no space

between my son and me, no gap of air, no expectation or disappointment, no failure or success: only what he was, ...my silent sometimes laughing companion, and my son" (Brown, p. 288).

Hornby (1992, 1995) described a wide range of reactions to their children's diagnosis of Down syndrome by eight fathers. These reactions included shock, disbelief, and an overwhelming response to a traumatic experience. However, these investigations also highlighted the fathers' shift in perspective once the initial shock of diagnosis had passed. In addition these fathers also described the positive aspects of raising children with disabilities including growth in fathering skills and a closer relationship with family members. Meyer (1986) and Miyamoto (1996) also discussed how fathers' constructive experiences with their disabled children positively affected family life.

The future is always unknown. A subtheme emerged from the main theme of *Learning to Dance in the Rain, The Future Is Always Unknown*. Fathers in this study described how they remained focused on the present instead of dwelling on the past as a way to "dance". No one ever knows what the future holds. All children face a future of unknown possibilities, and this is the same for children with an intellectual disability. Focusing on this "sameness" in all their children made it possible for the most part to avoid drowning in self-pity or depression as their children with intellectual disabilities did not meet developmental goals or expectations. Fathers were able to enjoy their children for their distinctive qualities and abilities.

Brown (2009) stated, "Raising Walker was like raising a question mark" (p. 10). His book opened as he described his son's first 8 years as "the same... the same routine of tiny details, connected in precise order, each mundane, each crucial" (p. 1). Each alternating night he and his wife traded care responsibilities while Walker lived at home, and Brown describes each as an enigma, during which anything could occur. He described the daily pattern in this manner:

"Early on I learned my son could lift my mood, that I responded to his unusual emotional valence" (p. 11). Elaborating Brown stated, "He took me into the darkness but he often was the way out of it as well" (p. 236).

Hastings and Taunt (2002) described key themes extracted from previous family research into these positive effects on family life from focusing on the present. They summarized these effects as 1) feeling pleasure in providing care for the child, 2) finding the child a source of happiness, 3) feeling a sense of accomplishment in doing the best possible for the child, 4) sharing love with the child, 5) taking the opportunity for personal growth, 6) strengthening the family, 7) having a new purpose in life, 8) developing social networks, 12) increasing spirituality, 13) clarifying what is important in life, and 14) making the most of each day lived at a slower pace. Others suggested the bidirectional influence fathers and children have on each other (Naseef, 1999), describing the realization a father had about the unconditional love his child deserved just being who he or she was meant to be (Lamb & Meyer, 1991). Lamb and Meyer explicated this realization by stating, "What a priceless lesson he has taught me in his silence, without words—like a Buddha" (p. 3). One father in an article by Dollahite states, "I think I'm a lot more conscientious about how I look at lots of people, look at other people in general" discussing people's worth beyond educational abilities (2001, p. 18). Finally, Olson, Dollahite, and White reported fathers believed themselves to have more empathy, patience, tenderness, and humility from fathering their children with special needs (2002).

Expectations don't change. A second subtheme inductively derived from *Learning to Dance in the Rain* was *Expectations Don't Change*. Fathers participating in this study described the need to maintain high expectations for their children's behavior and learning regardless of intellectual disability. They did not make exceptions for their children with intellectual

disabilities, but reported flexibility with the consequences when these children made poor choices or misbehaved. For example, one father held both children to the same standards about helping with chores around the home, but the child with the disability was given more chances to follow through with the assignment before the consequences were initiated.

Anderson and Weinhouse (1997) as well as Blomquist, Brown, Peersen, and Presler (1998) found that individuals with disabilities who were held to high standards for both behavior and education experienced more successes and were more likely to find areas of hidden potential. Others also reported that high parental expectations for their children's future had important effects on their children's behavioral development (Costigan, Floyd, Harter, & McClintock, 1997; Floyd & Phillippe, 1993; Sullivan, 1997). With high parental expectations children receive continual reinforcement for behavior and learning as parents tend to make correcting misbehavior and knowledge acquisition daily priorities.

Just Do What Needs Doing

The second main theme was *Just Do What Needs Doing*. Fathers described how it was necessary to learn and fully engage in fathering and other household skills quickly, to "get through the day, get through the night" (P-B). For some it was to assist their children's mothers in the new care-taking responsibilities; for others it was because the child's mother left or was medically unable able to do these activities. This engagement with household and child-care responsibilities was imperative with all children not only the ones with intellectual disabilities.

Brown (2009) described the experience of raising Walker in this way: "There is no planning with this boy. I go where he goes." (p. 285). He spoke to other parents of children with the same intellectual disability as Walker, and these other parents told him, "You do what you have to do" (p. 3). Brown described this as the easy part of raising a child like his son. He said,

"The hard part is trying to answer the questions Walker raises in my mind every time I pick him up. What is the value of a life like his-- a life lived in twilight, and often in pain" (p. 3). Similar to Brown and the other parents he writes about in his book, the fathers who participated in the study described their experiences as "jumping in" and doing whatever needed to be done to raise all their children as best they could.

Evidence suggests mindful and fully engaged parenting by fathers results in more responsibility for child socialization and may predict successful parenting in families who have children with intellectual disabilities (MacDonald & Hastings, 2010). Others agree that paternal commitment to children with special needs positively affects their children's development (Fewell & Vadasy, 1986; Marks & Dollahite, 2001). Nyman, Kaukola, and Kantojärvi (2000) ascertained from 12 fathers during six peer-group meetings the existence of three types of fathers. Not surprisingly, the type of fatherhood they termed "present" reinforced the positive aspects of becoming a father to children with disabilities. They described these positive aspects as a more developed emotional attachment, a deeper relationship with their partners, a more equal division of household and child care responsibilities, and a disappearance of the stigma from having children with disabilities. One father in Dollahite (2001) stated, "...as her father, I do whatever I can all the way around, making the best of the situation" (p. 19). Similarly, one father in Applebaum and Smolowitz's study stated, "My daughter's needs were so great that I really had to become an involved parent, not just saying I was one" (2012, p. 38). Finally, from a religious perspective, Dollahite (2003) in *Fathering for eternity* described the beliefs of 35 fathers who, following the doctrines of the Latter Day Saints, were more committed to loving and caring for their children with special needs in this life as they believed the relationship would continue into the next life. According to the researcher many fathers following the beliefs of

the Latter-Day Saints hold that children with disabilities are born that way and "divinely assigned" to a particular family to provide opportunities for "profound spiritual growth" (2003, p. 243). Similar to this, other researchers used the theme, "Faith" to describe how fathers discussed their feelings about their children's response to prayers and religious services (Applebaum & Smolowitz, 2012). About half of participant fathers expressed ideas similar to these, believing their children "extra special", and fully engaged in caring for all their children as entrusted to do so by their higher power. Accountability to self, wives, children, and this higher power proved an excellent motivator to "jump in" for some fathers in this study.

The Power of Patience

The strongest of all warriors are these two – Time and Patience.

-- Leo Nikolayevich Tolstoy

The third emergent theme from the fathers' experiences was *The Power of Patience* with a subtheme of *Keep Moving Forward*. To facilitate progress in their children, some ever so slowly, these fathers used patience to assist their children reach their highest potential-- wherever that might be. From a popular online resource, patience is defined as:

1. The quality of being patient, as the bearing of provocation, annoyance, misfortune, or pain, without complaint, loss of temper, irritation, or the like.
2. An ability or willingness to suppress restlessness or annoyance when confronted with delay: *to have patience with a slow learner*.
3. Quiet, steady perseverance; even-tempered care; diligence: *to work with patience* (dictionary.com, para. 1).

These fathers described situations in which perseverance and even-tempered communications with each of their children made all the difference in their understanding a

concept or meaning. Both anecdotal and research literature suggests patience is a much-needed characteristic for successful fatherhood. Parker described this characteristic of a "super dad" in this manner, "Patience, patience, patience. If I could wish for a booster shot of anything, it would be an extra dose of patience" (2012). Likewise, Sisco (2011) called patience the number ONE tool in the fatherhood toolbox, describing it as "the only thing that has pulled me through without going insane is patience" (para. 1).

Evidence from both qualitative and quantitative domains suggests patience is a quality with major impact on fathers' ability to raise their children. Olson, Dollahite, and White (2002) conducted a qualitative study including six fathers of children with special needs. Fathers reported using patience, tenderness, humility, and empathy to connect with their children. Others support these findings quantitatively concluding that patience results a large portion of father-child attachment at 6 and 12 months postpartum (Condon, Corkindale, & Boyce, 2008).

Nurturing Uniqueness

The final main theme inductively derived from the participant interviews was *Nurturing Uniqueness* with subthemes of *Help Them Find Their Own Path* and *Ability-Specific Learning*. These encapsulate fathers' experiences with their children with and without intellectual disabilities. These fathers highlighted their daily work of altering their fathering to fit each of their children's needs and abilities to facilitate each child's journey down his or her unique path. Regardless of intellectual ability each father described teaching his children at aptitude levels specific to each child and advocated for others to do likewise. This frequent adaptation to varying intellectual levels required flexibility on the part of each father as well as a keen sense of when to push and when to retreat.

Brown expressed the uniqueness of his son, Walker, as he cared for his son: "This is something you see; every time he is happy, he is as happy as he has ever been" (2009, p. 66), when discussing how his son enjoys the simplest object or interaction. With global delays caused by anomalies such as hydrocephalus and both hearing and vision impairments, only the present moment in time exists for Walker as "He has become the moment and it has become him, because he has nothing else to be" (Brown, p. 79). He elaborated later in his story on finding Walker's purpose, stating, "Walker is a lens—one with an unusual shape, I admit—through which to see the world more sharply...What if Walker is a work of art in progress—possibly a collective work of art?" (Brown, 2009, 242-243).

Brown also discussed his son Walker's path in his book. After caring for his son for many years, he and his wife grappled with the decision to place him in a group home. Brown even asked a shaman, a medicine man, "Should I let him go there?" "And the shaman said, 'It will change his path. But his path is his path; he has to go down his own path' "(Brown, 2009, p. 111).

During his journey to understand Walker, his father learned about the proximal zone of learning where Walker would be able to learn new skills. This zone is an element of the zone of proximal development (ZPD) as discussed in the sociological method of intelligence acquisition discussed in Chapter 2. Brown was told it would be difficult to find his son's zone considering Walker's profound intellectual disability. Despite this admonition, Brown said, "If I could find that zone, maybe I could teach Walker some crucial skills" (Brown, 2009, p. 230). After all his experiences with his son, Brown concludes this particular chapter with this: "The purpose of intellectually disabled people like Walker might be to free us from the stark emptiness of the survival of the fittest" (p. 234).

Literature in this area illustrates fathers' unending capacity to assist their children to reach their full potential. Hughes, Hughes, and Stamford (2008) described the father and son journey when the son is born with disabilities in *I am potential: Eight lessons on living, loving, and reaching your dreams*. Dollahite (2001) described the learning curve fathers undergo to expand their children's existing capacities. One participant in Dollahite's study stated, "Each child requires a father who will respond to his or her own needs" (2001, p. 19). In themes derived in their study, Applebaum and Smolowitz (2012) found that fathers moved past their lost hopes and dreams for their affected children by concentrating on "my beautiful unique child"(p. 38).

Reflecting the Theoretical

The investigator reflected on the theoretical perspectives discussed in Chapter 2 as having possible implications for the inductively derived themes from participant interviews in this study. Each theory is briefly summarized and discussed in the context of study findings as applicable.

Piaget's Theory of Cognitive Development

The theory of cognitive development describes the stages of intellectual development throughout childhood. Beginning with sensorimotor, knowledge acquisition is mainly through using the senses and learning to coordinate movement. The preoperational stage begins with the onset of speech and knowledge is concrete in nature. The third stage is concrete operational and commences with the ability to think logically but remains more concrete than abstract. Abstracting ability commences in the final stage when formal operations begin. Piaget described cognitive development in those with disabilities as following "the same rule of application, [but] follows a much slower rhythm and remains forever unfinished" (Piaget & Inhelder, 1947, p. 403). It is the child's ability to experience the environment that will determine how far he or she will progress (Payton, 2008).

Considering the main themes from the study, *Learning to Dance in the Rain*, *Just Do What Needs Doing*, *The Power of Patience*, and *Nurturing Uniqueness*, the investigator believes three of the four themes reflect Piaget's theory. *Learning to Dance in the Rain* with subthemes of *The Future is Always Unknown* and *Expectations Don't Change* depicts the study fathers learning to enjoy life despite intellectual disabilities in one or more of their children. Focusing on the positive aspects of their children despite delayed or halted progress in the stages of cognitive development, possibly due to an inability to experience aspects of the environment, is how these fathers have learned to dance in the rain despite what may happen next.

The Power of Patience, with the subtheme of *Keep Moving Forward*, describes how these fathers experienced their children's expanding abilities with patience and hard work. Regardless of whether or not their children possessed intelligence within the expected range, fathers described progress, however slow, they saw in all of their children. As some children were still quite young at the time of the interviews, only time will determine the full extent of their potential cognitive development and skill acquisition with the assistance of their fathers exhibiting patience in repeatedly exposing them to their environment and new challenges.

Similar to *The Power of Patience*, *Nurturing Uniqueness*, with subthemes of *Help Them Find Their Own Path* and *Ability-Specific Learning* portrays the fathers' actively working with each of their children differently to assist each in reaching their own unique potential. Celebrating and nurturing these differences allows fathers the flexibility to make conscious decisions for each child, both with and without intellectual disabilities, to support their cognitive development through repeated exposure to environmental cues. Each child is on his or her own unique journey on the continuum of Piaget's cognitive development theory facilitated by his or her own father.

Role Theory

Using the explanation of role theory from Chapter 2 to renew this discussion, role theory postulates that behavior is learned in the context of a particular environment. Functional role theorists believe society determines how individuals undertaking a certain role should behave. From the functionalist perspective, persons functioning in a particular role have internalized society's expectations of behavior while functioning in the role. Symbolic interactional role theorists believe it is the interaction between a person and the society in which he or she lives that determines role behavior. Reciprocal roles are also elements in either role theory perspective in which reciprocal roles such as father and child are required to successfully assimilate the role.

Using role theory in reflecting on the main themes inductively derived from the participant interviews, the investigator believes three of the four themes reflect the tenets of role theory. The strongest theoretical reflection is from the theme *Just Do What Needs Doing*. As the participants became fathers of children both with and without intellectual disabilities, they learned how to perform new tasks including child care, health-related procedures, or household duties out of desire or necessity. Some described a new role of child advocate within the health care system. As each father interacted with his environment and found himself in novel situations, he added new roles to his repertoire. As each child matured and changed, each father adapted however necessary to best assist his children in overall development and skill acquisition. A question posed during the beginning discussion on role theory was: What does a father do when his child cannot or will not reciprocate? In this study all participants were able to interact with their children, regardless of the intellectual disabilities present. Each child reciprocated with his or her father in his or her own ways. Fathers remained flexible and were determined to have this complementary relationship to whatever degree each child was able.

The Power of Patience and Nurturing Uniqueness themes also reflect the tenets of role theory as each describes the process of fathers using patience to help each of their children learn new tasks and responsibilities as they were uniquely able. In their roles as fathers to children at all levels of intellectual abilities, they described using patience to assist their children in learning their own roles as sons or daughters, siblings, patients, and contributing members of the household. Environmental interactions and high behavioral expectations formed the foundation for both fathers and children learning new roles. In summary, participants strived to provide their children with positive paternal role models.

Family Systems Theory

Proponents of family systems theory (FST) posit that the family is a single emotional unit in which all are affected by an experience occurring to any one member of the family. In discerning the connections and relationships between family members, behaviors by individual members are better comprehended. Two of the eight facets of FST, differentiation of self and birth order, were discussed in detail in Chapter 2 as most likely to explicate study findings. The investigator believes this connection occurred for all study themes.

Differentiation of self. The main theme *Learning to Dance in the Rain* depicts these fathers overcoming initial feelings of shock and sadness upon their children's diagnosis of intellectual disabilities to enjoy living, thankful for each child's abilities and the joys in life. When differentiation of self occurs or a differentiated person exists within a family, the individual is a separate self who can hold "beliefs, opinions, convictions and life principles" (Rabsteijnek, n.d., p. 6) while the undifferentiated family member "operates by rules, customs, and expectations..." (Rabstenjnek, n. d., p. 6). As differentiated members each individual is capable of keeping emotional influences from affecting intellectual thinking (Knauth, 2003) within the confines of the

familial emotional unit. Participant fathers spoke of their reactions to each child's birth and development regardless of intellectual ability and coming to the realization that each child represented a specialness that should be enjoyed not suffered. Fathers described their beliefs about child care and discipline, future hopes and dreams without making exceptions for the children with disabilities. They concentrated on current events not dwelling on the emotional aspects of their situations. These examples depict fathers who are differentiated selves working toward and focusing on the best for each of their children.

For these fathers differentiation of self within the second theme, *Just Do What Needs Doing*, meant concentrating on the activities necessary to survive each day with their children. Fathers repeatedly described themselves learning how to do new tasks and taking on new responsibilities to facilitate this survival. They felt free to move beyond the traditional father role of protector and provider, to take the road less traveled.

The Power of Patience, the third theme from the study, also reflected the tenets of paternal differentiation in the participants. In all they did with and for their children these fathers used patience and their desire to keep moving themselves and their children forward. They worked diligently to put aside the emotional aspects of child care to concentrate on obtaining the best for their children.

Nurturing Uniqueness is the final theme derived from the study data. It also reflects aspects of differentiation of self according to the Bowenian definition. Fathers portrayed themselves as willing to maintain flexibility in working with each of their children to highlight and strengthen their differences. They put a great deal of thought into decisions made for each such as the decision one father made to focus on cognitive and not physical therapies for his affected child. Most fathers described attending meetings with others working with their children to express their

personal beliefs about needed interventions. This ability and willingness to express personal beliefs instead of "going with the flow" epitomizes the differentiation of self in these fathers.

Sibling position. Although the methods in the current study included plans to discuss each child in order from oldest to youngest, the researcher did not focus on sibling position or birth order in children or parents per se. Little information emerged about sibling position from the fathers. There were, however, interesting differences in the affected children's positions within the family, which suggests further research is needed in the area. To reiterate from Chapter 3, P-A's affected child was the younger of two, P-B's the youngest of three, P-C's was the middle of three, P-D had two affected of three and were the oldest and middle, P-E's affected child was his third of four, P-F's were adopted and were both middle children, P-G's was the third of four, and P-H's affected child was the youngest of five. As eldest children tend to be leaders, middle children the peacemakers, and youngest children tend to be followers according to scientists who worked in this area, how do children with intellectual disabilities impact these tendencies in families with children having differing levels of intelligence?

Chronic Sorrow

During interviews, as the participants described the experience of having a child diagnosed with an intellectual disability, using words such as "sad", "shock", and "extremely difficult", the investigator began thinking about the theory of chronic sorrow. This theory describes recurrent feelings of sadness about an experienced or perceived loss when triggered by events such as birthdays, missed developmental milestones, or halted progress in cognitive development to remind someone of the loss event. As these fathers continued to discuss their children, they described their feelings entirely contrary to the patterns constituting chronic sorrow. The themes inductively derived in no way reflect this sadness or depression as described in the literature about

chronic sorrow. It is possible the participants did not discuss those times during the interviews, but that they had occurred. The investigator believes once the initial shock of diagnosis passed, these fathers did indeed alter their focus onto more current events.

Multiple Intelligence Theory

Eight different types of intelligences were described in Chapter 2 and constitute multiple intelligence theory. According to this theory, individuals can have talents in one or more areas, such as dance or mathematics and be completely imperceptive in other areas such as social interactions. At the beginning of the study, the investigator posed this question: Are fathers with children with and without intellectual disabilities more attune to the existence of multiple intelligences in those children? In other words, do these fathers actively search for areas of strength in their children? The researcher believes the theme *Nurturing Uniqueness* with subthemes of *Help Them Find Their Own Path* and *Ability-Specific Learning*, begins to reflect the theory of multiple intelligences.

Fathers described in detail working with each of their children to advance cognitive, physical, and emotional development. Using repeated exposure to areas of weakness such as crowds or loud noises, fathers assisted their children to overcome weaker areas. Although all fathers described starting early interventional therapies with their children, P-G made the choice to favor cognitive therapies over physical therapies, believing the physical would progress on its own given his affected child had older siblings. As no specific study data can be readily attributed to multiple intelligence theory, further research is needed in this arena.

Study Implications

This qualitative study was undertaken to describe the expectations and experiences of fathers as they raised their children with differing levels of intellect. Findings as described in

Chapter 4 provide greater understanding into fathers' perceptions of their child-rearing roles, responsibilities, and experiences. Because fathers and their experiences are of paramount importance to the lives of their children, these findings have implications for nursing practice, education, and future research.

Nursing Practice

Study findings suggest the need to develop paternal education and support programs to facilitate fathers' increased involvement with their children. Nursing professionals at all levels of practice provide care more holistically than other healthcare professions, believing the human being is more than the sum of its parts. Family centered care is the more holistic approach to pediatric nursing (Kovacs, Bellinb, & Fauria, 2006). Although some improvements have been realized in this area, nurses working with children must plan care and education for all members of their family, focusing not just on the mother and child dyad as frequently addressed in the literature (Kersh, Hedvat, Hauser-Cram, & Warfield, 2006). As one father stated, "Initially I was treated like a bystander, the man who drove the family to the clinic... I felt like the invisible man but worse because I was not invisible but ignored" (Smithson, n.d., para. 4). Another father stated, "I find that nurses, doctors, and therapists go to mom if they have a question. Because they figure that most women are more involved with the kids..." (Appelbaum & Smolowitz, 2012, p. 39). It is imperative for pediatric nurses to include fathers in the entire nursing process of care giving, realizing that fathers' perceptions may be much different from mothers', as perceptions evident in study results attest. A constructive relationship built on a professional rapport and mutual trust must be established with both parents if at all possible. Fathers who receive encouragement to become more assertive in their paternal role may feel more comfortable to do so. This necessitates nurses' mastery of therapeutic communication skills,

knowledge of cultural differences, and an awareness of personal biases. Nurses play a pivotal role in ensuring each parent's concerns are investigated and addressed and in making certain specific support mechanisms are put in place for all. Fathers need to be endorsed and celebrated by nursing professionals as vital in the lives of their children whether or not the child has an intellectual disability.

To facilitate fathers' inclusion in health care decision-making and the nursing process of caregiving nurses must advocate for changes in policy at the organizational, state, and national levels. Policies in need of change are any that result in negative consequences for the father and child relationship. It is through effective advocacy for these policy changes and professional relationships that fathers will feel supported sufficiently to speak up for their children.

Nursing Education

From a family systems theory perspective, each family member is affected by the birth of a child regardless of intellectual ability. Typical stresses of child birth and child care are compounded when an intellectual disability is suspected then formally diagnosed. Anticipatory guidance from nurses while working with each parent will assist in some stress alleviation and minimize unexpected changes in child care requirements, which in turn can positively affect the family as a whole. The nurse educator working with families and teaching those nursing students who eventually will work with these families must provide training and information in a manner specifically designed for each individual's learning style and cultural need. Effective engagement by each family member begins with involving each person at the beginning of the professional relationship and continuing with ongoing and proactive support throughout the entire nursing process. It is the nurse educator who can facilitate paternal inclusion in these endeavors.

In order to facilitate specific training and education for fathers according to culture and learning style needs, nurses must advocate for changes in educational policy. Policies must specify how paternal needs differ and speak to particular support mechanisms necessary to foster effective paternal engagement. It is not enough for agencies such as STEP-TN, the Tennessee Disability Coalition, and the East Tennessee Technology Access Center that specialize in assisting individuals with disabilities and their families to advocate for changes in policy. Nursing as a profession must also call for these educational policy changes.

Future Nursing Research

This study illustrates in some detail fathers' experiences with their children of varying intellectual abilities, from before birth in some cases. The results add to nursing science by bridging a gap apparent in the literature during the literature review by describing fathers' experiences and roles with children with and without intellectual disabilities in their own words. Mothers' perceptions were the secondary source of information previously used to represent fathers' or the entire family's viewpoints of living with children with and without intellectual disabilities.

From this qualitative endeavor, little specific data emerged from participant interviews to answer one question originally posed by the researcher: Are fathers of children with and without intellectual disabilities more attuned to the existence of multiple intelligences in their children? Further research focusing specifically on this area may enlighten nurses and others interested in multiple intelligences to tap into areas of potential in all children, but especially those with intellectual disabilities.

The investigator did not consider paternal perception differences possibly affected by birth order or gender of the affected child. Some literature exists investigating fathers' reactions

to sons versus daughters having the intellectual disability, but little if any research focusing on the affect of birth order in families with children of differing intellectual abilities has been completed. Future research into this area may encourage nurses to use anticipatory guidance, taking birth order of the affected child into consideration, for fathers experiencing the births of children with intellectual disabilities.

Finally, paternal age when confronted with the birth or discovery of a child with an intellectual disability is an area in need of further exploration. One father in this study was at least 10 years younger than other participants, and his perceptions were markedly different from the older fathers. As the researcher found only one study (Hartley, Seltzer, Head, & Abbeduto, 2012) delving into this area, it is unknown with any surety whether the father's age at the time of the diagnosis affected those perceptions, and further exploration may answer this question with more precision.

Transferability

The question of transferability must be considered in qualitative research (Lincoln & Guba, 1989) as transferability is an inseparable aspect of study trustworthiness. Miles and Huberman explain that a study's degree of transferability answers the question of the study's import to anyone other than the investigator and participants (1994). Although these eight fathers conveyed unique expectations and experiences of raising their children, the findings can only be transferable to those in similar contexts. The transferability, therefore, could be improved with the broad geographic area represented by the participants. In addition, as more than one ethnic background was represented in the participants, with a diverse age range and educational background, the degree of transferability is also enhanced.

Study Strengths and Limitations

This study closed a gap in the literature concerning fathers' expectations and experiences in raising children both with and without intellectual disabilities. Using qualitative description allowed the researcher to adapt and refine interview questioning as part of the iterative process to focus on areas emerging from previous interviews in the study. This process allowed participants to tell their stories of fatherhood as only they could.

Participants varied in age and education, increasing the transferability of the study. Participant diversity may assist in understanding how study results resonate with other fathers in similar situations and give hope that all is not lost when their child or children are diagnosed with intellectual disabilities.

Due to an inclusion error it was necessary to alter inclusion criteria denoted at the beginning of the research project. Original inclusion criteria specified that each participant must be his children's biological father; this criterion was overlooked with one participant in the latter stages of data collection. Once the error was realized, the East Tennessee State University Institutional Review Board (IRB) was notified. As the IRB found no additional risk to the participant in question, and this participant added to the study robustness, the inclusion criterion in error was altered to "Each participant was living with his children, whether the children were adopted, step, or biological, at least half time" as is included in Chapter 3 (Appendix K).

It is evident through qualitative research process literature that both the field log and reflective journal are of paramount importance in capturing the extensive contextual data abounding during one-on-one interviews. While these were used to some degree, the researcher did not keep them as up-to-date and organized as would have been prudent. It is possible therefore, that contextual data were not recalled that would have further informed study results.

Conclusion

Differences in intelligence have been recorded since about 1500 BCE in papyrus writings from Thebes, Egypt (Sheerenberger, 1983). The treatment of individuals with intellectual disabilities changes frequently and is linked to current beliefs and customs of the time. One unchanged aspect is the individuals and families who must incorporate the disabilities into their daily lives.

Previous researchers have typically investigated the effect of the disability by focusing on the mother's perspective or by using the mother's words to represent the entire family's perspective. Mothers are a secondary source where fathers' perspectives are concerned. It is through a broader focus into other family members that health professionals will make the most impact. This qualitative descriptive study provides a glimpse into the father's perspective of raising children who have differing levels of intelligence.

This study of eight fathers raising their children who may or may not be affected by an intellectual disability yielded four main themes: *Learning to Dance in the Rain, Just Do What Needs Doing, The Power of Patience, and Nurturing Uniqueness.*

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APPENDICES

APPENDIX A

Federal Regulations Timeline Increasing Access and Obtaining Rights

1943: The Vocational Rehabilitation Amendments commonly referred to as the *Barden-LaFollette Act*; increase the types of educational and vocational assistance available to people with disabilities through the federal rehabilitation program.

1963: The Developmental Disabilities Services and Facilities Construction Amendments to the *Mental Retardation Facilities and Community Health Centers Construction Act* passed by Congress. Contains the first legal definition of developmental disabilities and authorizes grants for services and facilities for the rehabilitation of people with developmental disabilities and establishes state “DD Councils.”

September, 1973: President Richard Nixon signs the *Rehabilitation Act* of 1973 making it illegal to discriminate against individuals with disabilities. Litigation arising out of Section 504 of this act gives such as “reasonable modification,” “reasonable accommodation,” and “undue burden”.

November, 1975: President Ford signs the *Education for All Handicapped Children Act* giving children with disabilities the right to a public school education in an integrated environment.

May, 1980: President Jimmy Carter signs *The Civil Rights of Institutionalized Persons Act*, giving individuals with disabilities residing in institutions through civil suits filed by the U.S. Justice Department.

1982: The Supreme Court rules in *Youngberg v. Romeo* that individuals with intellectual disabilities involuntarily held in state institutions have the constitutional right to safe conditions, freedom from unreasonable bodily restraints, as well as minimally adequate habilitation training while residing in state facilities.

1990: Congress amends the *Education for All Handicapped Children Act*, renaming the act the *Individuals with Disabilities Education Act (IDEA)*. IDEA is reauthorized in 1997.

July, 2003: The U.S. Access Board publishes updated Accessibility Guidelines, which set standards for building, sidewalk, restroom, parking, transportation design, and other areas of coverage. The new guidelines replace the 1991 guidelines and all earlier recommendations.

October, 2004: President George W. Bush signs the *Assistive Technology Act*.

December 3, 2004: President George W. Bush reauthorizes the IDEA (ecfr.gpoaccess.gov, 2012)

March, 2007: More than 80 countries sign on to the International Convention on the Rights of Persons with Disabilities during the convention's opening day. The United States, arguing that national laws already protect citizens with disabilities, refuses to sign.

March, 2009: Date designated by members of the Special Olympics for "Spread the Word to End

the Word,” an awareness effort against the widespread use of “retarded” as a casual insult (Burch, 2009).

October, 2010: President Obama signs "Rosa's Law" to make the term "mental retardation" disappear in exchange for "intellectual disability" under the IDEA legislation CFR §300.8(c)(6) (National Dissemination Center for Children with Disabilities, 2012).

APPENDIX B

Eight Concepts of Bowen Family Systems Theory

Triangles: In Bowenian theory, the triangle is considered the smallest familial relationship stable enough to withstand tension without having to move outside the triangle. However, it is also this triangle that can leave at least one member of the family "out" (The Bowen Center, 2011).

Differentiation of Self: The family system greatly influences each member's values, thinking, and behavior. If a member is poorly differentiated from the other member's, then this person is highly dependent on others' acceptance so behaves in a manner deemed acceptable to others, rarely thinking or acting for him or herself. The differentiated family member is an independent thinker, is not afraid to speak up, and guides his or her own thinking (The Bowen Center, 2011).

Nuclear Family Emotional System: This describes how a family copes with four main problem areas within a family, according to Bowenian theory. These areas are: (1) Marital conflict, (2) Spousal dysfunction, (3) Impairment of one child, and (4) Emotional distance (The Bowen Center, 2011).

Family Projection Process: The process by which children can inherit emotional problems from their parents. If a parent has anxiety about and focuses on an issue they fear has occurred within the child, then the child begins to act in the manner consistent with the feared behavior. Then the parent's fear is realized and treats the child as if the issue truly exists (The Bowen Center, 2011).

Multigenerational Transmission Process: This process describes how changes in levels of differentiation occur over many generations. The level of differentiation programmed into an individual while growing up affects their chosen spouse, and subsequently the differentiation of their children. As this is repeated, multigenerational changes in differentiation occur (The Bowen Center, 2011).

Emotional Cutoff: This is a means of protection by family members to deal with unresolved emotional issues. The less contact someone has with the person at the center of unresolved emotions, the less likely he or she will have to deal with the original issue causing the distress (The Bowen Center, 2011).

Sibling Position: Incorporating the work of Toman, Bowen believed sibling position in the family hierarchy effects the characteristics each child portrays. For example, many first-born children tend toward leadership while youngest children tend to be followers (The Bowen Center, 2011).

Societal Emotional Process: Bowen believed that each concept within his theory could also be applied to society as a whole. The emotional balance of society affects its behavior, especially during periods of regression and progression (The Bowen Center, 2011).

APPENDIX C

Research Study Flyer

Research Study: Expectations and Experiences of Fathers Who Have Parented Children With and Without Intellectual Disabilities



Study Summary:

The purpose of this study is to explore the expectations and experiences of fathers of at least two children— one developing as expected and the other having an intellectual disability.

Who Can Participate?:

- English speaking fathers of one child with and one child without an intellectual disability between the ages of 2 and 16 years.

What's Involved?:

- One 60-120 minute face-to-face interview

Benefits of Joining:

- Help researchers and other professionals working with fathers with children of differing intelligence understand their unique needs
- Flexible scheduling of interview time and complete confidentiality

Principal Investigator:

The principal investigator for this study is Jane K. Walker, RN, MSN, Nursing PhD student at East Tennessee State University

If you would like to volunteer for this study or request more information, please contact Jane K. Walker, RN, MSN by calling 865-805-2181. She can be reached by email at jane.walker@ws.edu

APPROVED
By the ETSU IRB

JUN 12 2011

By 
Chair/IRB Coordinator

DOCUMENT VERSION EXPIRES

JUN 11 2012

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APPENDIX D

Informed Consent Document

PRINCIPAL INVESTIGATOR: Jane K. Walker, RN, MSN

TITLE OF PROJECT: Expectations and Experiences of Fathers Who Have Parented Children With and Without Intellectual Disabilities

INFORMED CONSENT DOCUMENT

EAST TENNESSEE STATE UNIVERSITY INSTITUTIONAL REVIEW BOARD

This Informed Consent will explain about being a participant in a research study. It is important that you read this material carefully and then decide if you wish to be a volunteer.

PURPOSE:

The purpose of this research study is to explore the expectations and experiences of fathers of at least two children-- one developing as expected and the other having an intellectual disability. There will be no investigational drugs or devices used in this study.

DURATION:

You will be asked to participate in one face-to-face interview which will last about 60-120 minutes.

PROCEDURES:

The procedures will include one face-to-face interview between you and the researcher, Jane Walker. The conversations will take place in a place both you and the researcher agree on, in a private room. The conversations will be audio recorded. You can use your real name or an alias during the interviews, but a number will be assigned to each participant to identify the data on the recording. There will be no way to identify you by name when the interviews are complete. During this meeting you will be asked to talk about your experiences of being the father of your children, to which you may or may not respond. During the interview, the researcher may use a note pad to take short notes.

ALTERNATIVE TREATMENTS/PROCEDURES:

There are no other treatments or procedures offered for this project.

APPROVED
By the ETSU IRB

JUN 12 2011

By _____
Chair IRB Coordinator

04/12/2011

DOCUMENT VERSION EXPIRES

JUN 11 2012

ETSU IRB

Page 1 of 4

Subject Initials _____

PRINCIPAL INVESTIGATOR: Jane K. Walker, RN, MSN

TITLE OF PROJECT: Expectations and Experiences of Fathers Who Have Parented Children With and Without Intellectual Disabilities

POSSIBLE RISKS/DISCOMFORTS:

The possible risks or discomforts of your involvement with this study are minimal and comparable to other studies about parental experiences. Given that these experiences may be negative, the participant may experience some discomfort answering some questions. The participant has the right to decline answering any question in the interview. A toll free number for a crisis hotline will be made available to participants should the need arise.

POSSIBLE BENEFITS:

The possible benefits of participation in this project are the opportunity to talk about issues about becoming a father and experiencing children of differing intellectual abilities. Participation may help you develop ways of dealing with these experiences. This is your chance to tell the story of becoming a father. The results of being part of this project will add to the knowledge that is known about fathers' perspectives. Your part in this project may help health care workers develop ways to assist fathers as they experience situations similar to yours. At the conclusion of the study, results will be available to each participant upon request.

FINANCIAL COSTS:

The possible financial costs to you as a participant include the cost of gas to and from the interview site.

COMPENSATION IN THE FORM OF PAYMENTS TO RESEARCH PARTICIPANTS:

There is no payment of any kind for taking part in this project.

VOLUNTARY PARTICIPATION:

Participation in this research study is voluntary. You may refuse to participate. You can quit without impact or penalty but should do so before your interview is complete. If you quit or refuse to participate, there will be no adverse consequences. You may quit by calling Jane Walker, RN, MSN, whose phone number is 865-805-2181. There are no consequences of ending participation in the study.

APPROVED
By the ETSU IRB

JUN 12 2011

04/12/2011

By
Chair/IRB Coordinator

DOCUMENT VERSION EXPIRES

Page 2 of 4

JUN 11 2012

Subject Initials _____

ETSU IRB

PRINCIPAL INVESTIGATOR: Jane K. Walker, RN, MSN

TITLE OF PROJECT: Expectations and Experiences of Fathers Who Have Parented Children With and Without Intellectual Disabilities

CONTACT FOR QUESTIONS:

If you have any questions, problems or research-related medical problems at any time, you may call Jane K. Walker, RN, MSN at 865-805-2181, or Dr. Joy Wachs at 423-439-4549. You may call the Chairman of the Institutional Review Board at 423-439-6054 for any questions you may have about your rights as a research subject. If you have any questions or concerns about the research and want to talk to someone independent of the research team or you can't reach the study staff, you may call an IRB Coordinator at 423-439-6055 or 423-439-6002.

CONFIDENTIALITY:

Every attempt will be made to see that your participation and the research results in this project are kept confidential. When the data are transcribed, each person will be assigned an identification number, e. g. 1, 2, 3, and so on. This number will be assigned at the beginning of the first conversation with the researcher. Jane Walker, the primary researcher, will be the only person who knows the identity of the participant after the audio recordings have been coded. All recordings will be deleted after the study is completed. The typed data and other records will be stored in the locked office of Jane K. Walker, in a locked file cabinet for at least 5 years after the end of this project. The results of this project may be published and/or presented at meetings without naming you as a participant. Although your rights and privacy will be maintained at all times, the Secretary of the Department of Health and Human Services, the East Tennessee State University Institutional Review Board (for medical research), and personnel particular to this research (Jane K. Walker, RN, MSN, Joy E. Wachs, PhD, RN, PHCNS-BC, FAAOHN) have access to the study records. Your study records will be kept totally confidential according to current legal requirements. They will not be disclosed unless required by law, or as noted above.

APPROVED
By the ETSU IRB

JUN 12 2011

By 
Chair/IRB Coordinator

04/12/2011

DOCUMENT VERSION EXPIRES

JUN 11 2012

Page 3 of 4

ETSU IRB

Subject Initials _____

PRINCIPAL INVESTIGATOR: Jane K. Walker, RN, MSN

TITLE OF PROJECT: Expectations and Experiences of Fathers Who Have Parented Children With and Without Intellectual Disabilities

By signing below, you confirm that you have read or had this document read to you. You will be given a signed copy of this informed consent document. You have been given the chance to ask questions and to discuss your participation with the investigator. You freely and voluntarily choose to be in this research project.

SIGNATURE OF PARTICIPANT

DATE

PRINTED NAME OF PARTICIPANT

DATE

SIGNATURE OF INVESTIGATOR

DATE

SIGNATURE OF WITNESS (if applicable)

DATE

04/12/2011

APPROVED
By the ETSU IRB
JUN 12 2011
By 
Chair/IRB Coordinator

Page 4 of 4

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JUN 11 2012
ETSU IRB

Subject Initials _____

APPENDIX E

Institutional Review Board Approval



East Tennessee State University

Office for the Protection of Human Research Subjects ☒ Box 70565 ☒ Johnson City, Tennessee 37614-1707

Phone: (423) 439-6053 Fax: (423) 439-6060

Accredited Since December 2005

IRB APPROVAL – Continuing Expedited Review

April 13, 2012

Ms. Jane Walker

720 Clydesdale Avenue Seymour, TN 37865-4940

Re: Expectations and Experiences of Fathers Who Have Parented Children With and Without Intellectual Disabilities

IRB#: c0611.5s

The following items were reviewed and approved by an expedited process:

☐ Form 107 (xform - no conflict identified); Previously approved Narrative; Protocol History; ICD (ver. 04/12/11 stamped approved 03/23/12)

On March 23, 2012, a final approval was granted for a period not to exceed 12 months and will expire on March 22, 2013. The expedited approval of the study will be reported to the convened board on the next agenda.

The following **enclosed stamped, approved ICD** has been stamped with the approval and expiration date and this document must be copied and provided to each participant prior to participant enrollment:

☐ Informed Consent Document (Ver. 4/12/11 stamped approved 03/23/12)

Federal regulations require that the original copy of the participant's consent be maintained in the principal investigator's files and that a copy is given to the subject at the time of consent.

Unanticipated Problems Involving Risks to Subjects or Others must be reported to the IRB (and VA R&D if applicable) within 10 working days.

Proposed changes in approved research cannot be initiated without IRB review and approval. The only exception to this rule is that a change can be made prior to IRB approval when necessary to eliminate apparent immediate hazards to the research subjects [21 CFR 56.108 (a)(4)]. In such a case, the IRB must be promptly informed of the change following its implementation (within 10



working days) on Form 109 (www.etsu.edu/irb). The IRB will review the change to determine that it is consistent with ensuring the subject's continued welfare.

Sincerely,
Chris Ayres, M.A., Chair
ETSU Campus IRB

APPENDIX F

Transcriptionist Confidentiality Agreement

Confidentiality Agreement for Research Data Transcriptionist

Project Title: Expectations and Experiences of Fathers Having Children Both With and Without Intellectual Disabilities

Principal Investigator: Jane K. Walker, BBA, RN, MSN

Please initial boxes if in agreement with statement, and sign/date at the bottom.

- I understand that all the material I will be asked to transcribe is confidential.
- I understand that the content of the consent form, interview recordings, and interview notes can only be discussed with the researcher.
- I will not keep any copies of the information nor allow any third parties to access them.
- I will use a password protected computer and a locked file cabinet for hard copy materials.
- I will delete all interview and related notes/files from my computer after the transcription has successfully been given to the researcher.

Research Transcriptionist's Signature Beth L. Price (Gibson)

Research Transcriptionist's Printed Name Beth L. Price (Gibson)

Date: September 28, 2011

Primary Investigator's Signature Jane Walker

Primary Investigator's Printed Name Jane Walker

Note: The transcriptionist will be given a copy of this form for his/her records

APPENDIX G

Participant Screening and Background Information

Demographics

1. Participant

- a. Name (ensure confidentiality)
- b. Address (to mail informed consent document)
- c. Age
- d. Marital Status, years
- e. Occupation
- f. Education

2. Children

- a. Number of children
- b. Names
- c. Birth order of children- developing as expected vs. intellectual disability
- d. Specific intellectual disability
- e. When diagnosed

Background information to be obtained after initial contact with participant to determine inclusion criteria met. Once obtained, will mail informed consent prior to interview.

Interview Location:

APPENDIX H

Moderator Guide for Interviews

Moderator Guide for Interviews with Fathers of Children With and Without Intellectual Disabilities

Context of Interviews: The interview will take place in a private area in public location, mutually agreed upon by participant and researcher. Questions will be used to elicit the father's expectations and experiences of parenting children with differing intellectual abilities.

Introduction:

1. Mr. _____, thank you for agreeing to speak with me about your experiences as a father.
2. Can you tell me a little about (oldest child's name)?**

Guiding Questions:

1. Tell me about your experiences of being _____'s father.
2. What did you see as your role in _____'s upbringing?
3. Tell me about what it's like being _____'s father.
4. Can you tell me about the activities _____'s enjoys doing?
5. Tell me about the object you brought that reminds you of _____. OR Tell me about an object that reminds you of _____.
6. Tell me about activities that _____ enjoys.
7. As a father, what role do you think you have in helping _____ reach his or her highest potential?
8. Tell me your experiences in getting information you need to care for _____.
9. For any succinct response, the interviewer will ask, Can you tell me more about that?

** The interview will begin discussing the oldest child, progressing to the youngest after a short break. Discussing oldest to youngest regardless of which child has the intellectual disability.

Use of Guiding Questions:

Questions will be used to explore the expectations and experiences of fathers in their roles with their children. Questions will be used to facilitate exploration and not as a structured format. The interviewee will guide the interview and response from the interviewer will be kept to a minimum and only used to guide the interview forward.

APPENDIX I

Permission for the Use of *Welcome to Holland*

From: EPKingsley@aol.com [EPKingsley@aol.com]
To: Walker, Jane C.
Cc:
Subject: Welcome to Holland
Sent: Fri 2/1/2008 4:08 PM

Dear Jane:

So nice to hear from you. I'm so gratified to hear that "Welcome to Holland" resonated with you.

I am delighted to give you permission for you to reprint "Welcome to Holland" in your proposed dissertation for your pediatric nursing doctorate. I'm so flattered and pleased that you want to do so.

I have a couple of requests -

1. I am enclosing herewith a complete and accurate copy of Welcome to Holland so you can be sure you are using an "authorized version." It's been used in many places and in many versions. I would appreciate your reprinting it unchanged and uncut, using this official version.
2. Please credit me as the author, using my full (three-part) professional name: Emily Perl Kingsley and the copyright notice:

© 1987 by Emily Perl Kingsley

All rights reserved Reprinted by permission of the author

3. Please let me know that these conditions are acceptable to you.

Thanks again for your kind *words* about "Welcome to Holland." And very best of luck to you with your dissertation and your very wonderful career plans.

Sincerely,

Emily

EMILY PERL KINGSLEY

APPENDIX J

Permission for the Use of *Dreams*

JOHN COX ARTICLE

James May [jmay@seanet.com]

Sent: Saturday, January 29, 2011 2:50 PM

To: Walker, Jane C.

Greg Schell forwarded your request re: the use of the John Cox article. The article was originally printed in Exceptional Parent Magazine. I was the editor of the Fathers' Voices column and Mr. Cox wrote the article specifically for that column. He signed a letter of permission to have it printed. The article is now very old and I do not know the location/status of Mr. Cox or his children (now grown). The editor of Exceptional Parent at that time was Stan Klein, who is no longer affiliated with the magazine.

FWIW, you have my permission to use the article in your dissertation. The name of the article is "Dreams." My belief is Mr. Cox would be very pleased. Of course, full accreditation to Mr. Cox, the National Fathers Network and Exceptional Parent magazine is assumed. I hope this is helpful.

All the best. I appreciate your work, still very rare in the field.

James May Director (retired)
National/Washington State Fathers
Network www.fathersnetwork.org
A program of the Kindering Center
16120 N.E. 8th Street
Bellevue, WA 98008

Fathers Network My Three Wishes John Cox [coxjsl@gmail.com]

Sent: Friday, April 15, 2011 12:21 PM

To: Walker, Jane C.

<http://www.fathersnetwork.org/578.html>

Please feel free to use Dreams to support your dissertation. It sounds like a great topic. In case it is useful .. I included a link to a similar article titled My Three Wishes.

Best of luck on your dissertation and your career.

John Cox

Yes this is my husband his e-mail is .. JohnCox .. <coxjsl@gmail.com>.

On Fri, Apr 15, 2011 at 8:29 AM, Walker, Jane C. <Jane.Walker@Ws.edu>

wrote: > Dear Mrs. Cox,

I got your email address from Julie Widman (Kingsley) at the HOPE
> Infant Family Support Program, who I believe received permission
from > you. I am working on my doctoral dissertation entitled,
Expectations > and Experiences of Fathers Who Have Parented Children
With and Without > Intellectual Disabilities, and found a story called
Dreams by John Cox > on THEFATHERSNETWORK.org. I hope to use this in
the front portion of > my manuscript as an opening for the project.
Although I have received > permission from Mr. James May of the
National/Washington State Fathers > Network (retired), I obviously, do
not want to do so without
> ensuring I have Mr. Cox's permission as well.

>

>

>

> I was unable to locate him, but would like to ask his permission.
Can > you forward or discuss my contact information with him so that I
might > ask? I hope to gain a better understanding of fathers'
experiences as > only they can tell them.

>

>

>

> Thanks so much,

>

> Jane Walker

APPENDIX K

Institutional Review Board Review of Inclusion Error

To: Members of the ETSU Campus IRB

From: Jane Walker, RN, PhD candidate CON

Date: August 10, 2012

Re: c6011.5s-ETSU

Dear Members of the Campus IRB:

While preparing for my dissertation defense (08/03/2012) the day before, I read back over all chapters in their entirety. In reading chapter 3, I noticed the inclusion/exclusion criteria for my participants included this statement "Each participant must be their children's **biological** father". I left this off my participant screening form, and inadvertently included a participant (Participant F) whose children we discussed in our interview were **adopted**.

I believe this oversight on my part did not in any way pose any additional risk to this participant. In fact, his participation added to the richness of my data. I respectfully request to be allowed a minor modification to exclude the inclusion criteria that "each participant must be their children's biological father" and to replace it with "each participant must be living with the children discussed at least half time". Thank you for your consideration in this matter.



East Tennessee State University
Office for the Protection of Human Research Subjects • Box 70565 • Johnson City, Tennessee 37614-1707
Phone: (423) 439-6053 Fax: (423) 439-6060

IRB Acknowledgement

August 14, 2012

Ms. Jane Walker
720 Clydesdale Avenue
Seymour, TN 37865-4940

RE:	c0611.5s
TITLE:	Expectations and Experiences of Fathers Who Have Parented Children With and Without Intellectual Disabilities

The following report was reviewed by Chris Ayres, Chair, ETSU IRB, who determined that this event was not an unanticipated problem involving risks to subjects or others:

Event Identifier:	Inclusion of participant whose children were adopted rather than biological
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Thank you for reporting this event to the IRB Office.

Sincerely,
Chris Ayres, CHAIR
ETSU Institutional Review Board



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VITA
JANE CHRISTINA KUSMIK WALKER

- Personal Data: Date of Birth: December 27, 1968
Place of Birth: Hartford, Connecticut
Marital Status: Married
- Education: Hamblen County Schools, Morristown, Tennessee, 1973-1986
East Tennessee State University, BBA, Johnson City, Tennessee, 1990
Walters State Community College, AAS, Morristown,
Tennessee, 1993
East Tennessee State University, BSN, MSN, PhD, Johnson City,
Tennessee, 1999, 2004, 2012
- Professional Experience: Emergency Department, East Tennessee Children's
Hospital, Knoxville, Tennessee, 1993-2001
Pediatric Pulmonology & Respiratory Care, East
Tennessee Children's Hospital, Knoxville, Tennessee,
2001-2004
Associate Professor, Walters State Community College, Morristown,
Tennessee, 2004-present
RN Staff Educator, East Tennessee Children's Hospital, Knoxville,
Tennessee, 2005-present
- Publications: Walker, J. K. (2005). Overview of hospital-based
care, In Dunham-Taylor, J. and Pinczuk, J. (eds.) *Health Care
Financial Management for Nurse Managers: Financial
Applications in Hospitals, Long-Term Care,
Home Care, and Ambulatory Care*. Boston: Jones & Bartlett.
Dunham-Taylor, J., Lynn, C., Moore, McDaniel, S., & Walker J. K.
(2008). What goes around comes around: Mentoring new
nursing faculty. *Journal of Professional Nursing*, 24(6),
337-346.
- Honors and Awards: United States Department of Health and Human Services (DHHD),
Health Resources and Services Administration (HRSA), Bureau
of Health Professions (BHP) Research Award, 2010

Ambassador, National League for Nursing, 2007 to present

Sigma Theta Tau International Honor Society for Nursing, Omada Board
Leadership Program Scholarship, 2007-2009

Scholarship to present poster at 17th International Research Congress,
Sigma Theta Tau, Montreal, Quebec, Canada, 2006

Tennessee Nurses Association, District 2, Scholarship Award, 2006

Highest Academic Standing, College of Nursing, East Tennessee State
University, 2004