FAMILY HARDINESS, FAMILY COPING, AND MARITAL SATISFACTION AS REPORTED BY CAREGIVERS OF CHILDREN WHO HAVE BEEN DIAGNOSED WITH SIGNIFICANT DISABILITIES: A MIXED METHODS ONLINE RESEARCH STUDY

A DISSERTATION

SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS

FOR THE DEGREE OF DOCTOR OF PHILOSOPHY

IN THE GRADUATE SCHOOL OF THE

TEXAS WOMAN'S UNIVERSITY

DEPARTMENT OF FAMILY SCIENCES

COLLEGE OF PROFESSIONAL EDUCATION

BY

MIRANDA THORNTON, MS, MS

AUGUST 2018

DEDICATION

This endeavor has been long, arduous, messy, painful, and exhausting—much like labor. Thus, I dedicate this work to the one who gave birth to me, and the one to whom I gave birth (the first time, because from now on this thing will be my favorite offspring). To my mother, to whom this publication shall henceforth serve as all future birthday and holiday gifts, thank you for your unwavering and unconditional support. To my child: My sun has risen and set with you from the moment I knew about you. This process has been long, for both of us, but I would have never done it if it were not for you.

ACKNOWLEDGEMENTS

First and foremost, I must acknowledge and express a HUGE thank you to the families who made this dissertation possible! A special thank you to Kristy and Laci who helped pilot this study! The process of responding to these questions seemed to present various struggles to many people, but the vulnerability and honesty shown by respondents was so moving and touching! I shed many tears while reading about your experiences—even though (or maybe because) I have been there myself! Thank you all for sharing your stories, and for letting the other families out there who are like ours know that they are not alone, and for teaching those outside of our communities what special needs we, as families, have!

Next, I must acknowledge my committee. To all of you: You have all been so very patient, flexible, and supportive of me during my time at TWU. Especially the last few months! There has been a lot of hand holding, and space holding, and I truly appreciate this support! Each of you (even those whom I may or may not have threatened to strangle on one or more occasions…okay, it was definitely more!), I will forever be grateful for the role you played not only in getting this beast done, but also for the pivotal role you have played in my life. I would be embarrassed to count the number of times one of you has talked me off the ledge! (Or at least stopped me from dropping out of school and going back to waiting tables!) I once read something like, “A dissertation is temporary, a dissertation advisor is forever.” Each of you are now stuck with me, *forever*!

Dr. Erron Huey, before you were even on my committee, you were helping me out with this manuscript. I was so truly appreciative of your assistance. There were times I felt like I just needed to move into your office, I was there so much! I really felt like I owed you the moon for all the time, effort, and support you provided. Yet, every time I would express appreciation, you would just say something about it just being your job. All of that assistance was before you even agreed to be on my committee! Between allowing you on my committee, and this acknowledgement, though, I think we are even.

Dr. David Marshall, thank you, thank you, thank you, for retiring!! If it were not for you retiring, I would probably still be enrolled in dissertation. I *do* still have four more years to finish the PhD, after all. Alas, you are leaving us, so I must leave too. You have been incredibly patient while I took my time putting this project together, always available with open arms each time I would say "I'm ready now" even when I really wasn't. The TWU community will never be the same once you leave.

Dr. Linda Brock, now that I am graduating, I would really like to know how much I helped you expand *your* anxiety window! From the tears in Family of Origin to Sex Ed with Grandma and Grandpa, I will take away memories from TWU that are priceless. You are a fixture, although a generally quiet one, at TWU; I cannot imagine what my experience would have been like without you in it. It is important that I also thank you for not teaching over the summer, as again, I would probably still be "revising my final chapters" come the fall semester, were it not for that.

Last but not by any means least, the Chair of my Dissertation Committee, my second mom, the one whose emails I would cringe over when I had not written anything

recently, Dr. Linda Ladd. I don't even know where to start to describe the impact you have had on my life. As you know, the last ten years have been very challenging for me and my family. The monstrosities just seemed to rack up across the years, from the death of my dad my first semester to the hoops we jumped through these last few semesters, and all the unfathomable horrors in between. You have offered a type of support that I had never found before. I have grown so much since the first day I walked on campus, and so much of that I owe to you. While I did this *for* my child, I could not have done it *without* you, Linda. If I am ever able to offer a student half the support that you offered to me, I will feel blessed. You are truly stuck with me forever!...but I will probably never call you Linda again; that just feels like calling my mother by her first name!

In addition to my official committee, I would also like to acknowledge my unpaid support teams (unless you count the banana bread), first at school and then at home. Dr. Amy Sue Patrick-Ott, I thank you for allowing me to work with you on your project, and I appreciate you allowing me to use some of your qualitative data to complete this dissertation. My friends: Juana, Kristina, Sheeza, Melissa, Christina, Elise, Allison, Tesia, Carrie, John; you all have made this process bearable, from keeping me from losing all patience in the back of Jennings' classes, to sharing tears (I know, I spelled 'wine' wrong) over comps, to sharing rooms at conferences, to proof reading crap for me in the middle of the night! I am glad I got to enjoy these experiences with you and I hope to have many more! A special thanks to my two adoptive D* moms, Christina and Elise: Whenever I would spend just (what *you* thought was) a little too long online, I could always count on you to crack the whip. Thank you.

In my wildest dreams I could have never imagined the impact my family at TWU (including the illustrious Dr. Glen Jennings!!, so many more peers, and even those poor unassuming students who ~~were my guinea pigs~~ allowed me to hone my teaching skills over the last few years!) would have on my life. To say my life is better because of you all is the most pathetic of understatements!

Finally, I would like to thank the people who are the reason I ended up in family therapy to begin with, my family! School has literally been my life for nearly two decades. So many have passed in this time frame: Grandpa Henry, Grandma Edith, Aunt Judy, Aunt Norma, and my dad (the Pepsi man), Ron Thornton. I know they would love to be here right now, even if it were just to tell me to sit down and be quiet! To my family still here, I have missed many events because of school responsibilities (and a few because I really didn't want to go and just used school as an excuse). You never judged me (to my face) and were always supportive (I like to think). You all are always there when I get a little too big for my britches to remind me that I am "just Miranda." (But now, I am just Miranda with a PhD!) I appreciate you all being a part of the driving force in what got me to where I am today! Thank you. Steven, it has been a rough road, but I truly appreciate the support you have offered! Montana, get it together; it's your turn now! Mom. What a struggle this has been—for us both! I don't just mean school; we have had our downs, then our ups, but all of those helped me to become the person I am today. I cannot thank you and dad enough for that. I hope this makes up for all the tears I ever made you cry. Finally, Alex: You drive me crazy! Without you though, I do not know where I would be, which is why I haven't killed you yet. Yet.

ABSTRACT

MIRANDA THORNTON

FAMILY HARDINESS, FAMILY COPING, AND MARITAL SATISFACTION AS REPORTED BY CAREGIVERS OF CHILDREN WHO HAVE BEEN DIAGNOSED WITH SIGNIFICANT DISABILITIES: A MIXED METHODS ONLINE RESEARCH STUDY

AUGUST 2018

This online research mixed methods project was designed to explore, expand, and analyze the characteristics of families of children who have significant disabilities. Three concepts, family hardiness, family coping, and marital satisfaction, were analyzed in these families, in combination with qualitative reports of how the experience of raising a child with disabilities has affected the family system using the family stress model, the ABC-X model (Hill, 1949; McCubbin, 1987a; McCubbin, 1987b; Patterson & McCubbin, 1983). This research expands the previous research (Patrick-Ott & Ladd, 2010) which considered chronic sorrow, and ambiguous loss in families of children with significant disabilities. This present study has continued the qualitative exploration of raising a child diagnosed with significant disabilities and has gathered caregiver (92.6% parental) data from three quantitative surveys: The Family Hardiness Inventory (FHI), Family Crisis Oriented Personal Evaluation Scale (F-COPES), and the Kansas Marital Satisfaction Survey (KMSS). An “Original Group” of respondents provided demographic and qualitative data only, while a subgroup of this original group provided the mixed methods data. One qualitative theme “Perception” was drawn from the qualitative

responses of ten participants to the nine qualitative questions in this study; the two coders read their responses to determine if the participants had either a negative or a positive perception of their experience raising a child with a significant disability. The two responses, negative or positive, were quantified and analyzed using Pearson's correlation against their scores on the three quantitative instruments. There were significant correlations between all quantitative measures (i.e., F-COPES, FHI, and KMSS), resulting in the first three null hypotheses being rejected. There was also a significant positive correlation between the score for perception (dummy coded as 0 = negative and 1 = positive) and the scores on F-COPES, resulting in the final null hypothesis being rejected. Cohen's D was also run for effect sizes, where six interactions were found to have moderate to large effects ($d > 3$) (Gliner, 2017).

PREFACE

The first time I ever heard the “Holland” poem by Emily Perl Kingsley (1987), I was sitting in a presentation of a Dr. Michael DuPont’s doctoral dissertation. He had researched the experiences of families with children who have special needs. That was the first time I ever heard anyone put my experience into words—my son was then twelve. I sat in the back of that room, a room full of strangers, and tears rolled down my face. I knew then my area of research would be for families like mine.

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

TABLE OF CONTENTS

Page

LIST OF TABLES

Table Page

CHAPTER I

INTRODUCTION

Nearly one in five people have a disability, according to a 2012 report from the United States Census Bureau.

Recently, and perhaps due to the increased focus on multicultural counseling and competence within specializations under the family sciences umbrella, the attention of family scientists has turned to families who do not fit the typical mold that many of us "grew up" studying in our family therapy programs. Families from various cultural ethnic groups, LGBT families, immigrant families, families who practice a religion different than the norm of our society, single-parent families, and the emphasis of this paper—families of children with special needs—are now being focused on in our dissertations and peer reviewed journals. For decades, non-white, non-hetero, non-Christian, and non-typically developing families have had minimal focus in the literature, but all of that is changing (Baker, 2002; Gordon, 2009; Lindo, Kliemann, Combes, & Frank, 2016; Neely-Barnes & Dia, 2008; Opini, 2016; Robinson & Neece, 2015; Solomon & Chung, 2012; Stadler, Willing, & Eberhage, 1988; Twoy, Connolly, & Novak, 2007).

Yet, why would this shift be needed? Is the configuration, functioning, and development of families of children with special needs really any different, or more challenging, than the families previously studied in the field? As some of the newer research reveals, sometimes the answer is yes, they are different (Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005) but sometimes the answer is no (Baker, Blacher, &

Olsson, 2005) or there is little difference (Neely-Barnes & Dia, 2008). Clearly, this is a contradictory statement; yet it is supported by current research and is the very reason there needs to be more research on such families. Of course, more often than not, the answer is yes, raising a child with significant disabilities (SD) does increase the stress level for families when compared to families of typically-developing children (Gordon, 2009; Neely-Barnes & Dia, 2008; Robinson & Neece, 2015; Solomon & Chung, 2012; Twoy et al., 2007).

Aside from possible issues with samples studied, is it possible that the answer to this previous question truly is both yes and no? "Researchers have noted that marital and family functioning may be far more important predictors of parenting stress and depression than the presence or absence of childhood disability" (Neely-Barnes & Dia, 2008, p. 95). Being systemic thinkers, it would seem logical that what goes on in one subsystem will have an impact on other subsystems within the larger system (Hanson, 1995; Walsh, 2003; Watzlawick, Weakland, & Fisch, 1974). These changes, or lack of changes, may then interact with the systemic functioning of one subsystem (e.g., the children) or another (e.g., the parents), and eventually the functioning of the overall system (e.g., the family) (Greeff & Nolting, 2013; Hanson, 1995; Hill, 1949; Olshansky, 1962; Olshansky, 1966; Patrick-Ott & Ladd, 2010; Patterson & McCubbin, 1983; Solomon & Chung, 2012; Walsh, 2003; Watzlawick et al., 1974).

Multiple factors can impact how these systems interact: How the parties within the system speak to each other, the ways they interact with each other, even the way they think about each other (Greeff & Nolting, 2013; Hanson, 1995; Hill, 1949; Patterson &

McCubbin, 1983; Solomon & Chung, 2012; Walsh, 2003; Watzlawick et al., 1974). Positive and negative words, interactions, and even perceptions can have a significant impact on how the family functions (Hanson, 1995; Hill, 1949; Patterson & McCubbin, 1983; Walsh, 2003; Watzlawick et al., 1974). In fact, negative *thoughts* about the disability may actually be risk factors to focus on when working with a family (Neely-Barnes & Dia, 2008). This leads to the question: Does the family's, specifically the parents', thoughts about their child's disability actually have an impact on the functioning of the family?

Historically, many children with significant disabilities (i.e., disabilities that impact one's ability to function in daily life and often require extended caregiving) have been separated from their families of origin and institutionalized (Ray, Pewitt-Kinder, & George, 2009). In the 1960s children with significant disabilities (e.g., Down syndrome, mental retardation, cerebral palsy) were removed from their families as early as birth (Olshansky, Johnson, & Sternfeld, 1963). Even then, medical professionals began to wonder if this was in the best interest of the child, or the family (Olshansky et al., 1963). In this time period, Olshansky began researching families who had children with disabilities; at the time, the phrases *mentally retarded* or *mentally defective* were widely used and accepted, as can be seen in the articles (Olshansky, 1962; Olshansky et al., 1963).

In 1962, Olshansky wrote about his belief that parents of "mentally defective" children have a "persistent psychological reaction," which he termed *chronic sorrow* (p. 190). According to Olshansky (1962), parents would suffer chronic sorrow regardless of

whether their children were in the home or institutionalized. Olshansky (1962) went so far as to state that the experience of chronic sorrow was certain "among parents whose children are severely or moderately retarded," and that this burden might only end at the time of the death of either the child or the parents (p. 191). Olshansky (1962) went on to say that often parents were in denial about experiencing chronic sorrow, and that professionals, such as mental health professionals, would often see their sense of loss "as a neurotic manifestation rather than as a natural and understandable response to a tragic fact" (p. 191). In other words, while Olshansky (1962) saw this negative impact as an expected outcome, professionals of the time were more likely to pathologize this chronic sorrow.

This intangible loss is often overlooked by society at large, as it was by the professionals Olshansky (1962) mentioned. Boss (2006) termed a similar type of loss as *ambiguous loss*, but agreed that ambiguous loss and chronic sorrow describe different phenomena (Roos, 2013). Ambiguous loss occurs when a person is physically present, but mentally absent (as can be the case with children with SD), or mentally present, but physically absent (as can be the case with missing persons) (Boss, 2006, p. 7). In the case of families of children with SD, the loss of the parent's imagined child (pre-birth, or pre-diagnosis), is similar to Kingsley's loss of her trip to Italy (see preface; Ray et al., 2009). The parents of children with SD likely dreamed of a child who would develop along expected norms, and instead had a child who might not ever walk, or talk, or be capable of independent living (Ray et al., 2009). Yet, the parents still have their child, and may often be reminded of this (e.g., "at least you still *have* your child"), but they lost the child

they *imagined*. As this "loss" is not something that is recognized by society as a loss, such as if their child were stillborn or passed shortly after birth, it becomes an ambiguous loss (Boss, 2006). This ambiguous loss then becomes a chronic stressor, which may compound upon the already existent ongoing or chronic sorrow (Boss, 2006; Hill, 1949; Olshansky, 1962; Patterson & McCubbin, 1983).

In some instances, this loss of the imagined, typically developing child may be apparent immediately, as in cases of children born missing limbs, or born with Down syndrome, or other physical disabilities (Ray et al., 2009). However, in other cases, the loss may not be recognized until later in life, as may be the case with a child who is born looking to be typically developing, but later begins to show symptoms of mental illnesses or mental disabilities (Ray et al., 2009). In more significant cases of disabilities, this loss often becomes more evident as one compares aspects of expected life cycle development between typically developing families and those who may not be progressing through the expected stages (Patrick-Ott & Ladd, 2010; Ray et al., 2009). For example, as a mother of a child with cerebral palsy sees her friends' children learning to crawl, walk, or run, and sees her child falling further behind same-aged peers developmentally, her chronic sorrow may grow, and her ambiguous loss of having a child who would be like other children deepens. The father of a young adult child may begin to feel a sense of loss about ever walking his daughter down the aisle as he watches her develop schizophrenia and become less capable of living on her own due to her paranoia; he begins to let go of his imagined future with and for her.

As Olshansky (1962) stated: “The parents of a mentally defective child have little to look forward to; they will always be burdened by the child's unrelenting demands and unabated dependency” (p. 191). Often, these children need life-long care, hindering or perhaps even halting the family’s progression through the typical life cycle phases. In both examples above, the young child with cerebral palsy and the older child with schizophrenia, the children may never be capable of independent living, always requiring caretaking. This lack of progression through expected developmental stages has been termed *changelessness* (Olshansky, 1962; Olshansky, 1966; Patrick-Ott & Ladd, 2010). If the development of the child stalls or stops, how does the family adjust to this? What meaning does the family make of the child’s diagnosis and abilities? What happens to the family’s ability to cope with the challenges presented with caring for a child with significant disabilities? What happens to marital satisfaction and stress of the caretaking partners? How does having a child with significant disabilities affect the hardiness of the family system? These questions are the focus of this study.

Demographics of Families with Significant Disabilities

According to the United States Department of Health and Human Services (DHHS) (2013), over 11 million (15%) minor children have a chronic physical, developmental, behavioral, or emotional condition requiring special healthcare services. These children are found in approximately 23% of households (of households with children) in America (DHHS, 2013). Of course, this number only accounts for the minor children (i.e., under the age of 18), but children with SD often continue to require intensive care well beyond their 18th birthday. In other words, the number of homes with

adult children who still rely on caregivers for significant portions of their daily needs may greatly increase this number. Thus, this 15% reported by DHHS (2013) is likely under-representative of the number of families who are caring for someone who has SD when both adults and minor children are considered.

Every 10 years, the United States Census Bureau (USCB) conducts a national study designed to obtain information about residents in the country. This information is then used in various ways to obtain information about Americans, in general. However, the census, itself, is fairly basic and in 2010 only had ten questions on it (USCB, 2012). This does not give researchers much information about the general population. To address this, the Census Bureau also conducts the American Community Survey (ACS), which collects detailed information from a sample of Americans (USCB, 2012). While the ACS uses a different definition of disability than in this report, it is capable of producing estimates of the population with disabilities at subnational geographies like states, counties, places, and metropolitan areas (USCB, 2012).

According to an ACS in 2015, also conducted by the USCB (2016a), a total of 12.6% of families reported someone in the household with some type of a disability. Per the ACS, 12.5% of families in America reported raising a male with a disability and 12.7% reported raising a female with a disability (USCB, 2016a). Of those same families, the age range of the family member with a disability is as follows: A child under the age of five (0.8%), ages 5-17 (5.4%), ages 18-34 (6%), ages 35-64 (13%), ages 65-74 (25.4%), and 75 or older (49.8%) (USCB, 2016a). Collectively, 6.2%, of just under 40 million families, report that the person with a disability in the family is a minor, resulting

in approximately 2.5 million families in the United States raising a minor child with a disability (USCB, 2012; USCB, 2016a).

The families responding to the ACS reported the following types of disabilities for members of their family: hearing (3.6%), vision (2.3%), cognitive (5.1%), ambulatory (7.1%), self-care (2.7%), and independent living (5.8%) (USCB, 2016a). The following percentages were reported by families raising children under the age of 18 years: hearing (0.6%), vision (0.7%), cognitive (4.1%), ambulatory (0.6%), self-care (0.9%), and independent living (3.7%) (USCB, 2016a). According to the ACS, "difficulty with at least one activity of daily living (e.g., getting around inside the home, bathing, dressing and eating) was cited by 9.4 million noninstitutionalized adults; 5 million needed the assistance of others to perform such an activity" (USCB, 2012, p. 10). It is important to highlight the specification of *noninstitutionalized* adults; these are the adult who are still living in the home and being cared for by others (USCB, 2012). Also mentioned in this report, "15.5 million adults had difficulties with one or more instrumental activities of daily living (e.g., doing housework, using the phone, and preparing meals), of these, nearly 12 million required assistance" (USCB, 2012, p. 10).

Assuming that the percentage of persons with an independent living difficulty remains constant, nearly 6% of approximately 14 million families are locked in an ongoing care-taking role, whenever these parents choose to continue caring for their child with disabilities (USCB, 2016a). Thus, when the approximately 2.5 million families with a minor child with a disability are added to the reported 5.8% disabled adults who either live independently or in the care of others, approximately 2.3 million families are

affected. Based on these numbers, it would be safe to estimate that there are about 5 million persons with a reported disability currently being cared for by family members in the United States either because they are a minor or because their disability inhibits them from living on their own (USCB, 2012; USCB, 2016a). Of course, parents who choose to institutionalize their children, adult or minor, would no longer be responsible for caring for the individual on a day to day basis; yet, if the parents retain guardianship rights over the individual, the parents would still be in a caretaking role, even if only managing the individual's care from afar.

DHHS also reports on the ethnicity demographic of minor children with SD: Non-Hispanic Black children (17.5%), non-Hispanic White children (16.3%), American Indian/Alaska Native children (13.5%), Native Hawaiian/Pacific Islander children (12.3%), Hispanic children (11.2%), and Asian children (8.0%). Overall, the ACS (USCB, 2016a) reported slightly lower percentages per category, but also included additional categories of race (e.g., "other" and "two or more races"), which still totaled 12.6% of people in the US reporting a disability of some type.

According to DHHS (2013), families with children with SD are spread fairly evenly across income levels, with nearly 15% of families falling into each income level. This fact is based on the 2009 HHS Federal Poverty Guideline of $22,050 per year for a family of four (DHHS, 2013). According to the USCB; ACS (2016b), 73.9% of persons over the age of 16, who also reported having a disability, were not in the work force, while only 29.5% of those who reported no disability were unemployed (USCB, 2012). Of the group who reported a disability and also reported working in the last year, nearly

55% reported an annual income of less than $25,000, the adjusted poverty rate for the year this study was conducted (USCB, 2016b). According to the ACS report, just over 20% of those with a disability lived under the poverty level for the previous 12 months, while just under 12% of those who did not report a disability lived under the poverty level in this same time period (USCB, 2012; USCB, 2016b).

Children with Significant Disabilities

A disability can occur on any domain of development including physical (e.g., physical movement, cerebral palsy), cognitive (e.g., intellectual disability), or social (e.g., understanding social cues); this disability can significantly impact the individual's daily living skills (Bekenkamp, Klasina Groothof, Bloemers, & Tomic, 2014; Benzies et al., 2011; Greeff & Nolting, 2013; Lin, 2000; Ray et al., 2009). The phrase *significant disabilities* can have many meanings and seems to be described differently by nearly every researcher, but often includes disabilities that occur on more than one developmental domain (e.g., pervasive developmental disorder) (DHHS, 2013; Gordon, 2009; Greeff & Nolting, 2013). This lack of consistency in definitions between researchers is a limitation for the field and should be addressed in future research. In an effort to minimize contributing to this challenge in the literature, this research project will use the term SD as defined by the Individuals with Disabilities Education Act which emphases *concomitant impairments* (see p. 34 for full definition, 34 C.F.R. §30[b] [6]).

Children with SD, which may or may not occur on multiple domains of development, often need life-long care, locking the family into the developmental life cycle stage of perpetually caring for the disabled child. This is true if the parents retain

legal (i.e., guardianship) rights over the child, regardless of whether the parents continue to care for the child in their home or the child is cared for outside of the home (Gordon, 2009; Melnyk, Feinstein, Moldenhouer, & Small, 2001; Patrick-Ott & Ladd, 2010). Other children may be born, develop typically, grow and launch around the age of 18 from the family, but the family will forever be caring for the child with SD, often beyond the parents' deaths (Gordon, 2009; Neely-Barnes & Dia, 2008). Caring for the child with SD affects how the family functions for the remainder of that child's life (Benzies et al., 2011; Gordon, 2009; Patrick-Ott & Ladd, 2010; Neely-Barnes & Dia, 2008; Olshansky, 1962; Ray et al., 2009). Furthermore, caring for a child with SD could impact multiple generations as well including grandparents, parents, siblings, and perhaps even children of the siblings (Neely-Barnes & Dia, 2008).

For example, according to Twoy, Connolly, and Novak (2007), autism spectrum disorder (ASD) is the fastest growing developmental disability, with up to 1.5 million Americans being diagnosed with some form of autism. Solomon and Chung (2012) report that one in 91 children in the United States has been diagnosed with an ASD. Twoy et al. (2007) reported that The Autism Society of America estimated (2006) that the prevalence of ASD could grow to four million people in America, in the next 10 years (p. 252). ASD is a pervasive developmental disorder, and can affect the individual on multiple levels, but most often across their cognitive and social domains (Solomon & Chung, 2012; Twoy et al., 2007). However, children with ASD often have emotional and sometimes physical outbursts which can make integration of the child into social settings difficult (Solomon & Chung, 2012; Twoy et al., 2007). Solomon and Chung (2012) even report that parents

of children with ASD report higher levels of stress than not only parents of typically developing children, but also report higher stress levels than parents of children with other developmental disabilities. These families are also more likely to have reported lower marital satisfaction, as well as lower family functioning, which likely contribute to the nearly doubled rate of divorce among families of children with an ASD (Solomon & Chung, 2012). Furthermore, males (who are more likely to be diagnosed with ASD) are often larger and stronger than their primary care-givers (often the mothers), and as a result may be institutionalized for the safety of both the child and the parents (Solomon & Chung, 2012).

Relational Dynamics in Families of Children with Disabilities

In a study about parents of children with developmental disabilities, of children ages 2.5 to 5, Robinson and Neece (2015) found that the children's behavior problems were negatively correlated with parental psychological health and wellbeing. Robinson and Neece (2015) found that as parental stress went up, so did the children's behavioral problems, which together negatively correlated with the couple's reported marital satisfaction. Alternately, greater marital satisfaction was correlated with decreased parental stress, regardless of the child's behavioral patterns (Neely-Barnes & Dia, 2008; Robinson & Neece, 2015). Robinson and Neece (2015) stated that their findings highlight "high correlations between marital satisfaction, parenting stress, and child behavior problems, and highlights the need for a model that incorporates marital satisfaction into its understanding of parental mental health and child outcomes in families of children with developmental disabilities" (p. 39). Neely-Barnes and Dia (2008) echoed this stating

"that improvements in the child's behavior may lead to decreased parental stress and improved parental mental health" (p. 94). However, as Robinson and Neece started out with, such research connecting familial functioning to a child's diagnosis lacking.

Family Hardiness and Coping in Families with Children with Disabilities

In 2008, Neely-Barnes and Dia conducted a multi-cultural meta-analysis of literature published in the ten years prior about families caring for a child with disabilities and is a rare study that also included grandparents as caregivers. Neely-Barnes and Dia (2008) identified nurturing healthy family functioning as well as the meaning that families make of the child's disability to be imperative when working with these families. Neely-Barnes and Dia identified that parent's perceptions about the disability were correlated with the stress levels within the family, exhibited in the mother's functioning and marital satisfaction, specifically. Parents who had positive perceptions of the child's disability were less likely to report marital or familial stress, and less likely to report maternal depression (Neely-Barnes & Dia, 2008). However, parents who had negative perceptions of their child's disability were more likely to report the opposite, a negative correlation (Neely-Barnes & Dia, 2008). Thus, helping families adjust the meaning made of their child's disability can be an important intervention for family professionals. Neely-Barnes and Dia suggested the following areas for future research with families of children with disabilities: "More research into the impact of caregivers' positive perceptions of their child with a disability, specifically as they related to family coping; the experience of the care-givers other than parents; and a greater understanding of the individual experience of person caring for a child with a disability" (p. 103).

Theoretical Foundations for This Study

Systems Theory

According to systems theorists, everyone in a family is interconnected and subject to being affected by anything that effects anyone else in the system (Cox & Paley, 1997; Hanson, 1995; von Bertalanffy, 1968; Watzlawick et al., 1974). For example, conflict in one subsystem of the family, such as the sibling subsystem, can cause seemingly unrelated conflict within another subsystem, such as the couple subsystem, not to mention this same conflict may possibly cause conflict between the two subsystems (Cox & Paley, 1997; Fincham, 1998; Hanson, 1995; von Bertalanffy, 1968; Watzlawick et al., 1974).

In fact, Fincham (1998) went so far as to say that the way the child perceives the quality of the parent's marriage may affect the parent-child relationship, and vice versa. Fincham reported that the child's belief about the control they have over the parental relationship may further affect the parent-child relationship, as the child may attempt to intervene in the marital conflict, if the child believes they have control over this relationship—based upon his review of previous research. This same concept was echoed by Cox and Paley, when discussing boundaries between subsystems (1997). As a result, much like static electricity, the conflict may then be discharged via the child, instead of the marital dyad, where it originated—a primary tenant of systems theory (von Bertalanffy, 1968).

As discussed above, a child with SD could have an impact on multiple levels of the same familial system. As opposed to the child intentionally attempting to intervene in

the parental subsystem as described by Fincham (1998), the child with SD may be unintentionally affecting the parental subsystem by continuing to require supervision and or care-taking from parents well beyond the number of years care-taking may be required by a typically developing child of the same chronological age. Like with Finchman's scenario, though, this stress may be projected into other areas of the family system, such as the grandparental system, the sibling subsystem, or even systems external to the family such as doctors or schools (Bronfenbrenner, 1977).

Ecological Theory

In ecological theory, Bronfenbrenner (1977) suggested that individuals respond to and are impacted by relationships across several nested systems, such that individuals respond directly to other family members (microsystem) and systems in their daily lives (mesosystems). They also respond to influences coming from more distant systems (exosystems), and of course cultural influences (macrosystems) (Bronfenbrenner, 1977). Each of these systems then, could offer support (i.e., resources) or additional stressors for the family of the child with SD. Specifically, these nested systems are expected to be instrumental in the coping of families with children with SD, as these systems may offer support, additional stressors, impact the resources available to the family (e.g., availability of insurance coverage, additional funding, respite care, etc.) or have an impact on the meaning made by the family (e.g., such as feeling judged when out in public with their children).

Family Stress Theory

Similarly, scientists using family stress theory suggest that stressors that effect one person in the family will contribute to the overall stress load of the family and eventually impact everyone in the family (Hill, 1949). Originally identified as the ABC-X model by Hill (1949), the model was later expanded to a double ABC-X model, to allow for stress pile-up, which is often the case in families with children with SD, such as cystic fibrosis, as addressed in the original study by Patterson and McCubbin (1983). In the family stress model, the A represents the stressor, B is the resources, C is the perception, and X represents the outcome of either stress or crisis—mediated by the AB and C of the family (Hill, 1949; Patterson & McCubbin, 1983). A T double ABC-X model was also introduced by McCubbin and McCubbin (1987), which includes the same variables as the previous double ABC-X model, but also accounts for the family's type and level of vulnerability. These same concepts were later used to develop the Family Adjustment and Adaptation Response (FAAR) model (Patterson, 1988).

Patterson and McCubbin's (1983) double ABC-X model incorporates the stress pile-up, as previously mentioned, but also, the repeating or chronic nature of how these stressors that occur are mediated by resources and meanings made by family members, and then how remaining stress starts the process again (i.e., the stress pile-up) in a reciprocal, repeating nature (i.e., the "double"). While the family may manage an initial stressor (i.e., avoid a crisis state), such as a child not beginning to talk when same aged peers talk, the pile-up of stressors (Patterson & McCubbin, 1983) resulting from a child not able to ask parents for food when hungry, or the toilet when needed, will compound

as the child gets older and the situation does not change (i.e., changelessness) (Patrick-Ott & Ladd, 2010). This compounding of stressors (e.g., initial diagnosis, lack of progress through developmental stages, extended caregiving) will then contribute to any previous stressors (e.g., introducing a child into a family) and creates stress pile-up (Patterson & McCubbin, 1983).

The T double ABC-X model incorporates the typical ABC and X components, but also includes three other variables such as the life cycle phase of the family (McCubbin & McCubbin, 1987). The stressor (A), interacts with V, the family's vulnerability which is impacted by demand (e.g., stressors, transitions, and stains of family life cycle phase) pileup (McCubbin & McCubbin, 1987, p. 4). The A and V then interact with the T which is the family's typology (e.g., resilient, regenerative, rhythmic, balanced, etc.), which is a classification of the family's functioning (McCubbin & McCubbin, 1987). These three variables function as one variable group, which then interacts with the B and C, which are still the resources and perception, as well as a second variable group of PSC and the X (McCubbin & McCubbin, 1987). While the X is still the outcome, it is moderated by PSC, or the family's problem solving and coping responses (McCubbin & McCubbin, 1987).

For families with children with SD, they may not progress through the same life cycle phases as the typically developing families would, which has previously been termed changelessness (Olshansky, 1962; Patrick-Ott, 2011; Patrick-Ott & Ladd, 2010). According to McCubbin and McCubbin's (1987) version of the family stress model, this changelessness would be found under the T variable. However, McCubbin and

McCubbin (1987) also reported that a family's stress level varies, according to their life cycle phase. How this affects families who are locked into caretaking roles is unknown, but could likely increase the stressor buildup.

The FAAR model incorporated the double ABC-X model into a process model, in an attempt to describe the methods by which families achieve precrisis adjustment and postcrisis adaptation (Patterson, 1988, p. 208). The FAAR model states that the family will attempt to make small adjustments (i.e., the adjustment stage) to stressors until the stressors reach a level that homeostasis of the family is off balance to the extent, or for a length of time long enough that, the family enters a crisis state (Patterson, 1988). When these attempts do not restore homeostasis, the family moves into the adaption phase of the model, wherein "the family attempts to restore homeostasis by (1) acquiring new (adaptive) resources and coping behaviors, (2) reducing the demands they must deal with, and/or (3) changing the way they view their situation" (Patterson, 1988, p. 209). The FAAR model also considers the impact of normative (e.g., developmentally expected) and non-normative (i.e., unexpected) events (Patterson, 1988). Generally, a child born with SD would be considered a non-normative event, as most parents likely expect to birth typically developing children, at minimum during the early stages of pregnancy.

Collectively, all these versions contain the same three foundational components of the family stress model: The stressor(s), the resources, and the meaning made by the family, which affects the outcome (Hill, 1949; Patterson, 1988). In a family raising a child with SD, intrapersonal thoughts about these chronic and possibly compounding stressors (e.g., the child not learning to speak, the stress the child both feels and causes

from this changelessness) further adds to this stress pile-up of the initial stressor of a child not meeting expected developmental milestones. Other intrapersonal issues, such as the interpersonal relationships within the family (e.g., marital dyad) and its various subsystems (e.g., grandparents, schools, workplace) can be support pieces (i.e., moderators) or further contribute to the stress buildup. In other words, the family becomes locked into a continuous, cyclical process of stressors and stress pile-up, identification and accessing of resources, and meaning making of the situation, with the outcome of either stress or crisis (Patterson & McCubbin, 1983).

Ambiguous Loss and Chronic Sorrow

While not developed as independent theories, the concepts of chronic sorrow and ambiguous loss are instrumental in the understanding of the stressors for families of children with SD, which then factor into family stress theory. Chronic sorrow is a well-known concept (Olshansky, 1962) used to explain the continued loss experienced by parents of children with SD (Gordon, 2009; Patrick-Ott & Ladd, 2010). Chronic sorrow has long been associated with parenting children with SD, as the parents may be reminded on a daily basis that their actual child is not the same as their imagined/hoped for child (Gordon, 2009; Olshansky, 1962; Patrick-Ott & Ladd, 2010). Gordon (2009) even extended this concept to parents of children who have chronic medical conditions, aside from SD, as does the research by the DHHS (2013). In their article, Patrick-Ott and Ladd (2010) blended Olshansky's (1962) concept of chronic sorrow and Boss's (2006) concept of ambiguous loss to explain the ongoing, unresolvable loss felt by parents of children with SD.

It is important to recognize that this sorrow is a normal response to the ongoing loss felt by these families (Gordon, 2009; Olshansky, 1962; Patrick-Ott & Ladd, 2010). It is important to also differentiate chronic sorrow from grief and bereavement. In the case of children with SD, the loss is often not clear as it is emotional (e.g., the loss of the imagined child) rather than physical (e.g., the death of the child) as the loss associated with grief or bereavement would be. As mentioned previously, Boss (2006) has termed this "ambiguous loss." In the case of parents of children with SD, parents must grieve the "loss" of their imagined ideal child (Boss, 2006; Teel, 1991). Because the loss is not "real" according to social standards (thus, ambiguous), there is no prescribed social norm for grieving this loss, which can also lead to grief which can cause the individual to feel disenfranchised from their community. This often leaves parents floundering to create new meaning for their life and about the life of their child (Gordon, 2009; Patrick-Ott & Ladd, 2010).

All of these theories apply to the family caring for a child with significant disabilities. While only one person may have a significant disability, this disability will affect each person in the family, as described by ecological and systems theories (Bronfenbrenner, 1977; Hanson, 1995; von Bertalanffy, 1968; Watzlawick et al., 1974). Systems theory says each person within a family is connected with, and affected by, each other person within the family system (von Bertalanffy, 1968). Ecological theory says that this family, as a system, is also interconnected with various other systems the family interacts with (Bronfenbrenner, 1977). Family stress theory offers a formula through which to apply the concepts of chronic sorrow and ambiguous loss to the family and

ecological systems, as well as a rationale for identifying both stressors and resources (e.g., marital satisfaction, family hardiness, and family coping) within families of children with SD (Bronfenbrenner, 1977; Boss, 2006; Patterson & McCubbin, 1983; Olshansky, 1962; von Bertalanffy, 1968).

Statement of the Problem

Parenting any child is stressful; parenting children with SD increases the amount of stress on a family system (Greeff & Nolting, 2013; Hall et al., 2012; Robinson & Neece, 2015; Solomon & Chung, 2012). Realizing that one's child is not reaching the developmental milestones that same-aged peers are reaching can be a very difficult time for many parents (Hall et al., 2012; Neely-Barnes & Dia, 2008; Patrick-Ott, 2011; Patrick-Ott & Ladd, 2010), and may be affecting up to one-fourth of families in America (DHHS, 2013). When parents begin to realize that their child is not developing similarly to same-aged peers, they often begin to look for answers. Family specialists often lack developmental information about what may be helpful for families that are raising children who are not following developmental benchmarks. Furthermore, these family specialists may not have a grasp on how the family and child's development may be affecting marital satisfaction and family coping. The aim of this research project was to increase the knowledge that educators and clinicians have about the experiences of the couples and families who have children with significant disabilities.

Statement of Purpose

While research studies in the area of families with children with significant disabilities has been increasing (Greeff & Nolting, 2013; Hall et al., 2012; Neely-Barnes

& Dia, 2008; Patrick-Ott, 2011; Patrick-Ott & Ladd, 2010; Solomon & Chung, 2012; Twoy et al., 2007), the purpose of this study is to further explore as well as expand upon the relational dynamics of couples raising children with SD. Specifically, this was to be accomplished by expanding on Patrick-Ott's (2011) qualitative project with a larger, nation-wide population. However, the sample obtained was smaller than hoped, and may not be representative of a national population. Expanding on Patrick-Ott's (2011) research included this researcher's work in three areas: (1) family hardiness; (2) marital satisfaction; and (3) family coping, via quantitative measures (as described below). In addition, this researcher and co-coder reviewed a quota sample of the qualitative responses, to attempt to garner a more holistic depiction of what the experience is of families who are raising children with significant disabilities (Creswell & Plano Clark, 2007; Gliner, Morgan, & Leech, 2017). Specifically, this researcher and the co-coder looked for themes of negative or positive responses from participants, via consensus style coding, and analyzed this in relation to the quantitative measures such as the Kansas Marital Satisfaction Survey (assessment for marital satisfaction), to attempt to replicate previous research correlating the family's perception of the individual's disability and other family variables, such as marital satisfaction (Creswell & Plano Clark, 2007; Neely-Barnes & Dia, 2008; Ray et al., 2009; Solomon & Chung, 2012).

While there is a decent foundation of research addressing the coping skills of families of children with SD (Gordon, 2009; Hall et al., 2012; Neely-Barnes & Dia, 2008; Ray et al., 2009; Robinson & Neece, 2015; Solomon & Chung, 2012; Twoy et al., 2007), there are few studies that have used the Family Hardiness Index (FHI) (McCubbin,

McCubbin, & Thompson 1987b) and the Family Crisis Oriented Personal Evaluation Scale (F-COPES) (McCubbin, Olson, & Larson, 1987a) together, or used in a mixed methods research study, which Creswell and Plano Clark (2007) identified as preferable when attempting to describe holistic scenarios such as family functioning.

Research using the FHI is well defined, but across a variety of populations that does not include children with disabilities (Solomon & Chung, 2012). The FHI created by McCubbin, McCubbin, and Thompson (1996), is designed to measure the characteristic of hardiness as a stress resistance and adaptation resource in families which would function as a buffer or mediating factor in mitigating the effects of stressors and demands, and a facilitation of family resiliency adjustment and adaptation over time. As such, it fits well with the ABC-X model (Hill, 1949; Patterson & McCubbin, 1983) being used herein to attempt to explain how stressors, resources, and meaning function to manage stress levels within a family who is caring for a child with SD.

The F-COPES (McCubbin et al., 1987a) draws upon the coping dimensions of the Resiliency Model of Family Adjustment and Adaptation in which the following factors are integrated: Pile-up, family resources, and meaning/perception, the factors included in the ABC-X model (Hill, 1949; Patterson & McCubbin, 1983). Combined with the FHI, the F-COPES is expected to give a well-rounded picture of how families manage the stressors of caring for a child with SD.

Walter Schumm, developer of the KMSS, and other researchers, have used the instrument (in variable formats) and repeatedly found high consistency, reliability, and validity (Crane, Middleton, & Bean, 2000; Schumm, Crock, Likcani, Akagi, & Bosch,

2008; Schumm et al., 1986). The KMSS can be found in a three, five, and seven question formats, with seven possible Likert-style responses, with each format being found to be reliable in identifying marital distress (Crane et al., 2000; Schumm et al., 2008; Schumm et al., 1986). Data garnered from this measure are valuable informative but will also be helpful in looking for correlations between marital satisfaction and raising a child with SD, as well as to the meaning made of the child's disability.

The purpose of this study is to expand what is known about family hardiness, coping, and marital satisfaction in families of children with SD. Furthermore, this study is designed to further explore themes identified by Patrick-Ott (2011) regarding how families report their experience of raising a child with SD to combine these with the quantitative data in an attempt to create a more holistic representation of how families with children with SD function (Creswell & Plano Clark, 2007). Collectively, this study is designed to contribute to the research about families with children with SD, to aid helping professionals in understanding how these types of families differ from typically developing families (Gordon, 2009; Hall et al., 2012; Neely-Barnes & Dia, 2008; Ray et al., 2009; Robinson & Neece, 2015; Solomon & Chung, 2012; Twoy et al., 2007).

Research Questions

The overall research question asked in this larger mixed methods research project was: What is the experience of caregivers of children with significant disabilities? From this general question, this researcher asked the following four qualitative questions:

1. What is the experience of families raising children with significant disabilities (SD)?

2. What has been your (the parent's) experience in raising a child with SD?
3. What are your concerns, going forward, in raising your child with significant disabilities?
4. What do you wish helping professionals knew about raising a child with disabilities?

Hypotheses

The general research question guided the quantitative portion of this project as this researcher gathered quantitative data on marital satisfaction, hardiness (resilience), and perceptions of family coping from parents raising a child with a significant disability. The following hypotheses were tested:

1. There will be no statistically significant difference/relationship when scores on two instruments, marital satisfaction (KMSS) and family coping (F-COPES), are compared with marital status, income, age, and educational level of respondent, and age and gender of the child.
2. There will be no statistically significant difference/relationship when scores on two instruments, marital satisfaction (KMSS) and family hardiness (FHI), are compared with marital status, income, age, and educational level of respondent, and age and gender of the child.
3. There will be no statistically significant difference/relationship when scores on two instruments, family hardiness (FHI) and family coping (F-COPES), are compared with marital status, income, age, and educational level of respondent, and age and gender of the child.

Definitions

Chronic sorrow. This was first defined by Olshansky (1962) as the "observed psychological and emotional reactions of parents of children were mentally retarded. These reactions are natural, understandable, and nonpathological, and enduring for the child's lifetime" (p. 193). The symptoms of chronic sorrow include "periodic and inevitable exacerbations of intense emotional pain" (Olshansky, as cited in Roos, 2013, p. 22).

Coping. As used in the F-COPES, coping is defined as 1) the ways a family internally handles difficulties and problems between its members and, 2) the ways in which the family externally handles problems or demands that emerge outsides its boundaries, which allows the family to adapt to stressful situations more successfully (McCubbin et al., 1987a, p. 195).

Family Hardiness. Family hardiness specifically refers to the internal strengths and durability of the family unit and is characterized by a sense of control over the outcomes of life events and hardships, a view of change as beneficial and growth producing, and an active rather than passive orientation in adjusting to and managing stressful situations (McCubbin, McCubbin, & Thompson, 1987b, p. 125).

Marital Satisfaction. The Kansas Marital Satisfaction Survey (KMSS) (Schumm, Nichols, Schectman, & Grigsby, 1983) is a three-item measure designed to quickly assess marital satisfaction. As defined within the KMSS, the

construct of marital satisfaction is defined in three ways: Satisfaction with the marriage, the spouse, and the marital relationship.

Significant disabilities. These are also known as multiple disabilities and severe multiple disabilities. The Individuals with Disabilities Education Act (34 C.F.R. §30[b] [6]) describes a significant disability as one with concomitant impairments (such as mental retardation, blindness, mental retardation and orthopedic impairment, like cerebral palsy, and others). The combination causes severe problems so that the individual cannot be accommodated in special programs solely for one of the impairments. [For example:] Caregiving duties that extend past the infancy stage into the adult years (continued spoon feeding, incontinence, continued supervision, poorly developed self-help skills, etc.), are all associated with raising a child with significant disabilities.

Assumptions

1. Online respondents met the research inclusion criteria.
2. Respondents answered questions honestly.
3. Children identified by parents as being significantly disabled truly meet the criteria outlined in the definition.

Delimitations

1. Participants were the primary caretaker (e.g., parent, step-parent, grandparent, guardian, adult sibling, extended family member or guardian) of a child diagnosed with SD that lived in their home at least 11 months of the year; of persons (e.g.,

children) with significant disabilities (SD), as defined in the Individuals with Education Act (34 C.F.R. §30[b] [6]);

2. Participants were at least 18 years old; and
3. Participants did need access to the internet to complete the survey; thus an internet connection and a device to access the internet was required and may have limited the participants.

Summary

Overall the challenges of parenting a child with SD may never seem to end or change as these children may not learn to feed themselves, dress themselves, or advocate for themselves, locking parents into a never-ending care-taking role (Hall et al., 2012; Neely-Barnes & Dia, 2008; Patrick-Ott & Ladd, 2010). Parents often never progress through the expected family development stages of raising adolescents, launching children, or having grandchildren (Neighbour, 1985). This lack of change has prompted some researchers to use the term *changelessness* (Olshansky, 1962; Patrick-Ott, 2011; Patrick-Ott & Ladd, 2010). This changelessness may result in increased levels of depression for the caretakers, which of course would have a cyclical effect on the caretakers' availability to care for the person with SD, as well as an impact on the various relationships the caretaker is involved in (Greeff & Nolting, 2013; Solomon & Chung, 2012).

Collectively, the theories and concepts outlined above are combined to attempt to explain how having a child with SD may affect a couple and family, from the individual level (i.e., of the parent), to the multiple subsystems within the family (e.g., parental,

sibling, grandparent), to the external subsystems in the society in which the family lives as well as how marital satisfaction, family hardiness, and family coping may mediate or even contribute to the stress level within a family. Furthermore, Creswell & Plano Clark (2007) reported that the mixed methods research style provides for a better understanding of the issue than using qualitative or quantitative data alone. This research project attempts to identify if this is in fact true, as well as how the family manages these, and other stressors associated with raising a child with SD. Even with the increases of recent research in the domain of families raising a child with SD, more research is needed to build a more holistic picture of what is it like to parent a child with SD, with special focus on marital satisfaction, family coping, and family resilience. The purpose for this research project was to further explore as well as expand on the information available to professionals who work with families regarding the experience of raising a child with SD.

CHAPTER II

LITERATURE REVIEW

Like in The Holland Poem (Kingsley, 1987), Patrick-Ott found herself in a land she had not anticipated going to, when she began realizing her son was not developing along with his same aged peers (Patrick-Ott, 2011). Throughout her progression through the curriculum for her masters and then her doctoral degree, Patrick-Ott became aware of the concepts of the "normal" family life cycle, chronic sorrow, and ambiguous loss and applied them to her own life, and finally her own research (Boss, 2006; Olshansky, 1962; Patrick-Ott & Ladd, 2010). Olshansky (1962) introduced the concept of chronic sorrow in relation to parenting a child with disabilities, and suggested this continued reaction was normal for many families. In more modern language, Olshansky (1962) suggested that helping professionals must recognize this as *normal* chronic sorrow, which is the experience of ongoing sadness while parenting a child with special needs.

Patrick-Ott's (2011) dissertation focused on blending these concepts of ambiguous loss and chronic sorrow, and this project is designed to expand on the information identified in her research (Patrick-Ott, 2011; Patrick-Ott & Ladd, 2010). In her research, Patrick-Ott (2011) identified nine original themes: "(1) reaction to the diagnosis, (2) barriers (medical and informational), (3) adjustment (spousal, family, siblings, extended family), (4) resiliency, (5) supports (extended family and community), (6) hope, (7) future, (8) chronic sorrow, (9) individual adjustment" (p. vi). These nine

themes were then compared to the concepts presented in Boss's (2006) work and condensed into seven themes:

(1) The Initial Reaction of Chronic Sorrow to the Diagnosis

(2) Finding Meaning in an Overwhelming Situation

(3) Tempering Mastering of Parenting a Child with a Disability

(4) Normalizing the Ambivalence of Parenting

(5) Parents Restructure their Identity

(6) Discovering Hope in the Redefined Family, and

(7) Ambivalence about the Future" (Patrick-Ott, 2011; p. vi).

In their research, Solomon and Chung (2012) wrote about parents' reactions as they attempted to get a diagnosis for their children; in their study, they categorized responses to inquiries about the process of finding a diagnosis into three themes. "Wait and see" was where parents would express concerns about their child's development, but the professionals would minimize or dismiss the parents' concerns, suggesting the parents just wait and see how things turn out (Solomon & Chung, 2012).

> Tanya took her 18-month-old son, Eli, to the doctor for an ear infection. While there, she told her doctor that she was worried Eli had autism. The doctor asked, "Does he point?" During story time, when Tanya would say, "Eli, where's the cow?" Eli would point to the cow. So, she answered yes. The doctor told her that he does not have autism, and Tanya felt relieved. Eli would go on to receive an autism diagnosis at 26 months. (Solomon & Chung, 2012, p. 254).

The theme of “just a speech problem” included experiences of parents who would seek professional help, would be referred to another professional, who would then just treat one or more of the symptoms, never referring the family for a full neurological evaluation (Solomon & Chung, 2012). The example given for this was a 28-month-old child who was using very few words, who was referred by a medical professional to a speech pathologist who treated the child for a communication disorder for many months before suggesting a full evaluation (Solomon & Chung, 2012, p. 254).

The third theme identified by Solomon and Chung was “getting the news.” This related to the day the parents of the children were given the diagnosis, such as autism. Often, parents would refer to this time period as “life before” and “life after” learning of their child’s diagnosis, regardless of if the parents suspected their child had autism prior to the assessment or not (Solomon & Chung, 2012, p. 255). Parents in this study also expressed concerns with how the news was delivered, what information regarding treatment options were given (if any), and what (if any) treatment plan was developed by the medical professional (Solomon & Chung, 2012). Sometimes “getting the news” can occur after the child is born, as described above, but sometimes the news may happen before the child is born, as was the case for Julia Pewitt-Kinder (Ray et al., 2009).

As the mother of a child with disabilities herself, Pewitt-Kinder shared her experience of “getting the news” (Solomon & Chung, 2012) in her article about working with parents of children with disabilities (Ray et al., 2009).

> “There’s no good way to tell you. Your baby has down syndrome,” said the pediatrician. My world instantly stopped, and I felt a black fog closing

> in. I couldn't move or breathe or speak. The only sound I heard was my husband sobbing. My first thoughts were "No, I can't do this. How do we go from expecting a perfectly healthy baby to receiving a stranger?" Finding out that our daughter Ella had down syndrome was like being told that the baby we dreamed of had died and now we had a child we knew absolutely nothing about (Ray et al., 2009, p. 16).

This was the moment that Pewitt-Kinder realized she (and her husband) was on her way to Holland, and not Italy (Kingsley, 1987).

When the diagnosis is given, though, the impact has just begun for the family; now they must learn to live in Holland (Kingsley, 1987; Ray et al., 2009). Solomon and Chung (2012) and Ray, Pewitt-Kinder, and George (2009) recommended diagnosing clinicians refer to family therapists as treatment resources, to help parents navigate multiple service providers and develop comprehensive treatment plans, as well as processing all the information that accompanies a significant diagnosis (whether from the helping professionals, or from the parents' own research) (Neely-Barnes & Dia, 2008). Pewitt-Kinder continued in sharing her own experience of receiving the diagnosis for her daughter: "As Ella's parents, we experienced a range of new emotions in this transition from the [in home treatment plans] to the [treatment plans within the school]; We felt sad, tired, concerned, angry, and surprised" (Ray et al., 2009, p. 19).

From the therapeutic side, Solomon and Chung (2012) suggested that family therapists focus helping parents with taking action in their day to day and home lives, making meaning of their child's diagnosis, and how this impacts their relationships, as

well as processing emotions relating to the child's diagnosis and how these emotions can pull the couple closer together or drive them apart. Ray et al. (2009) echoed this need for professionals in other arenas, such as educators, to work collaboratively with families in learning how to navigate the multiple systems they may need to obtain services for their children. Pewitt-Kinder wrote:

> When working with families of children with special needs, you may encounter parents who appear angry, confrontational, mistrustful, or questioning about your [intervention] methods. Do not take this personally! Historically, families have had to be their own advocates for an appropriate [treatment] for their children with disabilities, and some families you are working with may have had negative experiences with the system in the past. [However], listening to families is key in working with them as partners in supporting the learning and development of their child with special needs (Ray et al., 2009, p. 21).

Chronic Sorrow

Olshansky (1962) introduced the concept of chronic sorrow in relation to parenting a child with disabilities and used this concept to explain the continued loss experienced by parents of children with significant disabilities, and suggested this continued reaction was normal for many families. He wrote extensively about how these parents would feel ongoing, and piling, stress related to caring for children with disabilities (Olshansky, 1962). Gordon (2009) extended this concept to parents of children who have chronic medical conditions, aside from SD, as does the research by the

DHHS (2013). Patrick-Ott and Ladd (2010) blended Olshansky's (1962) concept of chronic sorrow and Boss's (2006) concept of ambiguous loss to explain the ongoing, unresolvable loss felt by parents of children with SD.

Ambiguous Loss

Boss (2006) introduced the concept of ambiguous loss and suggested that it can occur in two different ways, each leading to a similar outcome. One pathway occurs when a loved one is unavailable psychologically, but present physically, such as through Alzheimer's disease or being in a coma (Boss, 2006). The second possibility is when the loved one is unavailable physically, but available psychologically (Boss, 2006). An example of this would be in missing person cases, when someone is imprisoned, or even military parents stationed away from their families. The outcome for either situation is a sense of loss, without the traditional means of closure. For instance, in most American cultures, when a person dies, a funeral is held. People whose loved one is missing are denied the closure offered by a funeral and are in a perpetual state of not-knowing (ambiguity) the whereabouts of their loved one (Boss, 2006).

For a family with a typically developing child, the family life cycle follows a well-researched path. Most families progress through various, predictable life cycle stages: Couples unite, have children, raise and then launch children, become grandparents, and later pass on—hopefully before one's children (Gilbert, Lankshear, & Petersen, 2008; Neighbour, 1985). These later stages, though, hinge on the child being capable of self-care and independent living which often occurs in the launching phase. Yet, children with SD often do not launch from their homes (DHHS, 2013; Gilbert et al.,

2008; Gordon, 2009; Hall et al., 2012; Patrick-Ott & Ladd, 2010; Olshansky, 1962). When these children fail to launch from the home, the parents (and likely other family members) become stuck in a care-taking role, which has been characterized by the changelessness of the situation (Gilbert et al., 2008; Hall et al., 2012; Neely-Barnes & Dia, 2008; Patrick-Ott & Ladd, 2010; Robinson & Neece, 2015).

It is important for family professionals to recognize that chronic sorrow is a normal response to the ongoing loss felt by these families (Olshansky, 1962), not only from the possibly missed life cycle changes of launching a child, but from any and all other missed developmental milestones (Gordon, 2009; Hall et al., 2012; Patrick-Ott & Ladd, 2010). Children with SD may miss other socially and developmentally expected life cycle phases, such as graduating from school, finding a partner, or having their own children, which may also cause the parents a (perhaps additional, compounding) sense of loss. The parents of these children (and possibly even grandparents) are likely to have an ongoing, chronic, sense of loss throughout these multiple life stages, that typically developing children will pass through, which may be reignited (i.e., a buildup) throughout their life as they are presented with reminders that their child is not “typical” when they watch other’s children navigate these stages (Olshansky, 1962; Neely-Barnes & Dia, 2008; Robinson & Neece, 2015).

It is important, though, to differentiate chronic sorrow and ambiguous loss from grief and bereavement (Olshansky, 1962). In the case of children with SD, the loss is often not clear as it is emotional rather than physical, which is where the blending of the concepts of chronic sorrow and ambiguous loss are applicable (Patrick-Ott & Ladd,

2010). As mentioned previously, Boss (2006) has termed this “ambiguous loss.” In the case of parents of children with SD, parents must grieve the “loss” of the child they expected, imagined, or hoped to have (Boss, 2006; Greeff & Nolting, 2013; Ray et al., 2009; Teel, 1991). Because the loss is not “real” (thus, ambiguous), there is no prescribed social norm for grieving this loss, and often parents are actually discouraged from processing this grief (e.g., “at least you still *have* your child”), which can also lead to grief which can cause the individual to feel disenfranchised from their community (Ray et al., 2009).

This often leaves parents floundering to create new meaning for their life and about the life of their child (Greeff & Nolting, 2013; Hill, 1949; McCubbin & McCubbin, 1987; Patterson & McCubbin, 1983; Neely-Barnes & Dia, 2008; Patrick-Ott & Ladd, 2010; Patterson, 1988; Robinson & Neece, 2015). This meaning is important in both Patrick-Ott and Ladd’s (2010) research, as well as the family stress model’s component of meaning making as a mediator for stressors (Gordon, 2009; Hill, 1949; Patterson & McCubbin, 1983).

A combination of systems theory, ecological theory, and family stress theory have been used to describe how these multiple stressors may be affecting families of children with SD, with an emphasis on how a systemic approach to treating these families is imperative (Bronfenbrenner, 1977; Boss, 2006; Hanson, 1995; Hill, 1949; McCubbin & McCubbin, 1987; Patterson, 1988; Patterson & McCubbin, 1983; Olshansky, 1962; von Bertalanffy, 1968; Watzlawick et al., 1974). According to Solomon and Chung (2012), “the family therapist carries important expertise about systemic dynamics and adaptive

coping" and as such is positioned well to work with families of people with disabilities (p. 251). Furthermore, Ray et al. (2009) recognized other professionals who interact with the family as important in this helping process as well (e.g., teachers, hired caregivers, case managers).

When considering individuals with SD, who often cannot care for themselves, understanding the family that is a part of their care system is paramount (Greeff & Nolting, 2013; Neely-Barnes & Dia, 2008; Ray et al., 2009; Robinson & Neece, 2015). Familial involvement in treatment has repeatedly been found to correlate to better outcomes for people receiving a variety of treatments (DHHS, 2013; Greeff & Nolting, 2013; Gordon, 2009; Hall et al., 2012; Neely-Barnes & Dia, 2008; Ray et al., 2009; Robinson & Neece, 2015; Solomon & Chung, 2012). According to Solomon and Chung (2012), family therapists, with their training in systems and adaptive coping, are uniquely positioned to work with families of someone with a disability.

Considering the system that the individual with SD exists within will give practitioners a fuller picture of what resources they are working with (Gordon, 2009; Hall et al., 2012; Neely-Barnes & Dia, 2008; Ray et al., 2009). When speaking of the stressors families of children with SD face, Solomon and Chung (2012) reported "parents face problems in multiple domains (accessing supportive/therapeutic/educational services, balancing work and family, and dealing with powerful feelings, to name a few), and an integrative approach allows family therapists to flexibly address interrelated problems or constraints" (p. 251); this notion is echoed by Ray et al. (2009). As family specialists, understanding how families with children with SD vary from typically developing

families, is even more important (Neely-Barnes & Dia, 2008; Ray et al., 2009). Canary (2008), in a meta-analysis, identified nine themes across the articles reviewed that described factors that affect families of minor children with disabilities: “Wellbeing, resources and socioeconomic factors, culture and minorities, intervention programs, extended families, siblings, professional support relationships, religion, and the interface of policy” (p. 413). Knowledge of the specific struggles more often faced by families of children with SD is important for specialists working with these families. Overall, family specialists, and family therapists specifically, are well poised to assist these types of families (Neely-Barnes & Dia, 2008; Ray et al., 2009).

Theoretical Support

Per systems theorists, members of a family are interconnected, and affected by anything that effects anyone else in the system (Cox & Paley, 1997; Hanson, 1995; von Bertalanffy, 1968; Watzlawick et al., 1974). Conflict is easily discharged from one member of a family to another, or from one subsystem to another within a family (Cox & Paley, 1997; Fincham, 1998; Hanson, 1995; von Bertalanffy, 1968; Watzlawick et al., 1974). Ecological theory suggests that families exist within several nested systems, such that individuals respond directly to other family members (microsystem) and systems in their daily lives (mesosystems) but also respond to influences coming from more distant systems (exosystems), and of course cultural influences (macrosystems) (Bronfenbrenner, 1977). For families, these inter-nested systems, may offer support, or increase the stressors for the family of the child with SD. Family stress theory suggests that stressors

will pile-up, in a recursive version of the original ABC-X model (Hill, 1949; Patterson & McCubbin, 1983).

In the ABC-X model, the A represents the stressor, B is the resources, C is the perception, and X represents the outcome of either stress or crisis—mediated by the A, B, and C of the family (Patterson & McCubbin, 1983). However, Patterson and McCubbin's (1983) double ABC-X model incorporates the stress pile-up, and how this chronic stress (e.g., chronic sorrow, chronic ambiguous loss) may affect the family. Other intrapersonal, interpersonal, and inter-systemic issues may also contribute to the stress pile-up of the family (Patterson & McCubbin, 1983). As such, the family, and its various subsystems, may very well become a stressor, and contribute to stress pile-up; however, the family can also be a resource (Hall et al., 2012; Neely-Barnes & Dia, 2008; Ray et al., 2009; Robinson & Neece, 2015; Solomon & Chung, 2012).

Using the family stress model to interpret these factors can be very helpful (Patterson & McCubbin, 1983). For example, an abundance of any of these factors—say extended families—could mediate the stress pile-up resulting from a grown child who is unable to move independently, feed themselves, or toilet themselves, as extra family members may be available to stay with the grown child so that the parents are able to work, go on a date night, or even spend time with other children (McCubbin & McCubbin, 1987; Patterson & McCubbin, 1983). However, if the extended family members are critical of the parents' care-taking of this same grown child with SD, the extended family members may then be a stressor (McCubbin & McCubbin, 1987; Patterson & McCubbin, 1983).

Collectively, these stressors, resources, and the meanings made by the family members combine to result in an outcome somewhere on a continuum of 'just' stress to that of a crisis, with a crisis generally culminating in the halt of family functioning (McCubbin & McCubbin, 1987; Patterson & McCubbin, 1983). Patterson and McCubbin (1983) stated the outcome occurred on a continuum, from bonadaptation to maladaptation, with the idealized result of bonadaptation (i.e., growth), in the double ABC-X model. Thus, in addition to family specialists having knowledge of the specific struggles more often faced by families of children with SD, understanding what factors help families to cope with these stressors, and therefore avoid a crisis state, are important for these professionals as well.

Family Coping

Coping is defined as "1) the ways a family internally handles difficulties and problems between its members, and 2) the ways in which the family externally handles problems or demands that emerge outsides its boundaries, which allows the family to adapt to stressful situations more successfully" (McCubbin et al., 1987a, p. 195). It was hypothesized by McCubbin, McCubbin, and Thompson (1987b) that "families who have coping behaviors in both areas operate with more coping skills and will adapt to stressful situations better" (p. 195). Via application of Hill's (1949) model, McCubbin et al. (1987b) view the family as "a unit which reacts to stress, and uses resources available to the family, in order to manage stressors" (p. 195). Some of these resources may include social support networks, extended family members, friends, neighbors, or even internal resources such as their approach to problem solving (McCubbin et al., 1987a, p. 195).

Resilience

Resilience as, defined by Knestrict and Kuchey (2009), is the “family's ability to withstand hardships and rebound from adversity while becoming more strengthened and resourceful” (p. 228) has been found to be consistently present in families who seem to be coping well with a child with SD, to the point that a child with a disability has even been found to have a positive impact on the family (Greeff & Nolting, 2013; Hall et al., 2012; Solomon & Chung, 2012; Walsh, 2003). In other word, resilience is something that may help families from moving into the crisis/maladaptation state of the family stress models (Hall et al., 2012; Hill, 1949; McCubbin & McCubbin, 1987; Patterson & McCubbin, 1983; Patterson, 1988; Walsh, 2003). McCubbin and McCubbin (1988) defined resilience as the “characteristics, dimensions, and properties which help families to be resistant to disruption in the face of change and adaptive in the face of crisis situations” (p. 247), which can result in maladjustment or bonadaptation.

McCubbin and McCubbin (1988) went on to say that resilient families are those that can return to the pre-crisis level of functioning, at minimum, after the stressors level out. Therefore, resilience can allow a family to return to the same functioning level they were at prior to the stressor(s), or to grow from it (i.e., bonadaptation) (McCubbin & McCubbin, 1987; McCubbin & McCubbin, 1988; Patterson & McCubbin, 1983). A family whose functioning level dropped below that of the level prior to the introduction of the new stressor (e.g., in this case, an initial diagnosis, or perhaps even the caretaker beginning to realize the child was not reaching milestones), would be considered to have maladjusted, and if family functioning stops, the family may be considered to be in crisis

(Hill, 1949; McCubbin & McCubbin, 1987; McCubbin & McCubbin, 1988; Patterson & McCubbin, 1983; Patterson, 1988).

Knestrict and Kuchey (2009) found that resilient families possessed seven major characteristics: Rules, routines, rituals, criterion referencing, reconfiguration, tenacity, and socio-economic status. Rhythmic patterns (e.g., those based on rules, routines, and rituals), specifically, were found to increase resiliency within families with children who have SD (Greeff & Nolting, 2013; Knestrict & Kuchey, 2009; McCubbin & McCubbin, 1987; Solomon & Chung, 2012). Another important factor in resilience was having the time to reflect on one's situation (Knestrict & Kuchey, 2009; Neely-Barnes & Dia, 2008). Yet, this time is often a luxury to many of the lower income families (Greeff & Nolting, 2013; Neely-Barnes & Dia, 2008).

Outcomes

Similarly, Lin (2000) reported on how family coping contributed to general outcomes in families of people with cerebral palsy (CP). Lin used McCubbin, McCubbin, and Thompson's (1987b) resiliency model of family stress, adjustment, and adaptation and the family life cycle theory (Duvall, 1962; Turnbull & Turnbull, 1997) to assess families of persons with CP. According to McCubbin et al.'s model (1997), a family will use all available resources in an attempt to maintain homeostatic level of functioning in the face of stressors—CP, in the case of Lin's study. Lin found five primary coping factors, via the F-COPES, which were important for the families in her study: "positive family appraisal, support from concerned others, spiritual support, personal growth and advocacy, and positive social interaction" (p. 211). Interestingly, Lin also found that the

coping strategies used in the families in her study varied with the life cycle the family was in (e.g., increased positive family appraisal in families with school aged children, but increased knowledge in younger children). It is important to note that the majority of the children focused on in Lin's study were school aged, with the average age of eight.

Social Support

Like Lin (2000), Twoy et al. (2007) also used the F-COPES, and applied the resiliency model of family stress, adjustment, and adaptation (McCubbin et al., 1987a). In Lin (2000) and Twoy et al.'s (2007) studies, the authors assessed families of children (age 12 and under) who had been diagnosed with ASD. ASD is characterized by behavioral outbursts, and delays in social skills—of course, ASD occurs on a continuum, and symptomology depends on the severity of the disorder (Solomon & Chung, 2012; Twoy et al., 2007). However, these behavioral outbursts may be why "mothers of children with autism experienced more distress than mothers of children with intellectual disabilities without autism" (Twoy et al., 2007, p. 253). Interestingly, these same participants reported their most common coping skill was "distancing and escape, a behavior aimed at withdrawal from a stressful situation" (Twoy et al., 2007, p. 254).

Again, like Lin's (2000) results, Twoy et al. (2007) found that social support was a primary coping skill by these families, as well as passive appraisals, reframing, and spiritual support. Passive appraisals (i.e., ignoring the problem or believing there is nothing the family can do about the issue), and relying on one's God or church community, seem to have been highly correlated in Twoy et al.'s study. Limitations for this study, though, included a participant group who were all married, with the majority

aged 31-50, who were also educated with higher than normal incomes—the majority were also non-Caucasian with most speaking English as a second language (Twoy et al., 2007). Clearly these limitations make generalization of this information challenging; however, these coping skills and the resilience reported in this article seems to be consistent with other researchers, even though other researchers may not have researched the same specific disability (e.g., Lin, 2000 and Cerebral Palsy, and Solomon & Chung, 2012; and Twoy et al., 2007 with ASD).

Taanila, Syrjälä, Kokkonen, and Järvelin (2002) also reviewed resilience and coping in families of persons with disabilities. In addition to a key set of coping skills parents used (e.g., "information and acceptance, good family co-operation, and social support"), Taanila et al. also found that families that appeared to be coping well had a larger variety of coping strategies available to them (p. 80). Information and acceptance was related to the parent's perception (e.g., accuracy) of the information they received about their child's disability as well as their own acceptance of this diagnosis, which often included an aspect of hope for their child's future (Solomon & Chung, 2012; Taanila, Syrjälä, Kokkonen, & Järvelin, 2002). Other important resources included family cohesion and cooperation, social supports, and other personal resources (Solomon & Chung, 2012; Taanila, et al., 2002). Again, though, the life cycle phase of the family played a role in the resilience demonstrated by the family, specifically, the age at which the child was diagnosed; the later in life when the diagnosis was received, the poorer the outcome for the family (Taanil et al., 2002).

Families Struggling to Cope

The emotional, physical, and financial toll of having a child with SD is immeasurable, and can often seem exhausting, unending, and alienating (Baker-Ericzen, et al., 2005; Bekenkamp et al., 2014; Gordon, 2009; Patrick-Ott & Ladd, 2010; Solomon & Chung, 2012). When discussing ASD specifically, Twoy et al. (2007) stated, "the day-to-day level of stress arising from parenting, the parents' lack of confidence in handling the child's behavior, the lack of supportive services to meet the needs of the affected child, and the realization that there is no cure for ASD are but a few of the stressors that are experienced by the parents" (p. 252). In addition to these, families of children with SD also face the same stressors that typically developing families face (e.g., finances, work, extended families, interfacing with multiple systems external to the family). It is clear to see how a family raising a child with SD could become overwhelmed.

A child with a disability will have an impact, of course, on the parents, in accordance with systems theory, from the increase of stressors related to the care of the child, the demand on resources including time and finances, to the mental strain imposed requiring the new meanings to be made of each individual's life within the system (Bronfenbrenner, 1977; McCubbin & McCubbin, 1987; Neely-Barnes & Dia, 2008; Patterson, 1988; Solomon & Chung, 2012; von Bertalanffy, 1968). This in turn, will have an impact on how the parents function—from their parenting style, ability, and availability to others in the family, to their couple relationship, each of these individually can be a stressor or a resource for the parents in the family (Baker-Ericzen et al., 2005;

Bronfenbrenner, 1977; Neely-Barnes & Dia, 2008; Robinson & Neece, 2015; Solomon & Chung, 2012; von Bertalanffy, 1968).

Additionally, though, the parent's perception will also have a reciprocal effect on how the system functions (Bronfenbrenner, 1977; Hill, 1949; Patterson & McCubbin, 1983). Canary's (2008) meta-analysis also reviews perception of support and diagnosis, and how it impacts family functioning:

> Mothers of high-functioning children experienced less distress when they perceived high levels of available social support than did mothers of low-functioning children, but perceptions of low levels of available social support were associated with higher levels of distress in mothers of high-functioning children and lower levels of distress in mothers of low-functioning children (p. 414).

Clearly, all levels of support from within and external to the family, have an impact on not only how individuals function within the family, but also how the couple functions as a subsystem and how the family functions as a whole.

Stress. Families of children with SD have been shown to suffer more stress (Baker-Ericzen et al., 2005; Greeff & Nolting, 2013; Hall et al., 2012; Neely-Barnes & Dia, 2008; Olshansky, 1962; Solomon & Chung, 2012; Walsh, 2003), more financial difficulties (Baker-Ericzen et al., 2005; Neely-Barnes & Dia, 2008; Robinson & Neece, 2015; Solomon & Chung, 2012), more health problems, more isolation (Baker-Ericzen et al., 2005; Hall et al., 2012; Solomon & Chung, 2012), limited energy, increased anxiety (Baker-Ericzen et al., 2005), sleep deprivation, uncertainty about the future (Hall et al.,

2012; Olshansky, 1962), struggles with handling problem behavior (Greeff & Nolting, 2013; Neely-Barnes & Dia, 2008), and increased frustration at the general lack of understanding (Hall et al., 2012; Neely-Barnes & Dia, 2008; Solomon & Chung, 2012), when related to families who do not have children with special needs (Archuleta, Britt, Tonn, & Grable, 2011; Bekenkamp et al., 2014; Benzies et al., 2011; Darling, Senatore, & Strachan, 2012; Gordon, 2009; Greeff & Nolting, 2013; Ouellette-Kuntz et al., 2014; Patrick-Ott & Ladd, 2010; Roper, Allred, Mandleco, Freeborn, & Dyches, 2014; Solomon & Chung, 2012; Teel, 1991). Parents of children with SD are likely to report higher levels of familial and marital stress than parents of typically developing children, which in turn, can have a cyclical affect, including an impact on the sibling dyad (Baker-Ericzen et al., 2005; Greeff & Nolting, 2013; Hanson, 1995; Neely-Barnes & Dia, 2008; Robinson & Neece, 2015; Roper et al., 2014; Solomon & Chung, 2012).

Siblings

Siblings of children with SD are subject to these same stressors, in addition to a few others (e.g., parental stress/availability, teasing by peers, care-taking responsibilities), which has an additional and separate impact on these siblings (Giallo & Gavidia-Payne, 2006; Roper et al., 2014). These siblings may also report a more distant relationship with the child with disabilities, dependent upon the specific disability and the quality of the parenting couple's relationship (Giallo & Gavidia-Payne, 2006; Roper et al., 2014). Specifically, children with autism and *multiple disabilities* (i.e., other physical and intellectual disabilities) were found by Roper et al. (2014) to increase caregiver burden and decrease cohesion in the sibling subsystem. However, a diagnosis of down

syndrome, specifically, was linked to an increase in warmth, and less reported quarrelling, between siblings (Neely-Barnes & Dia, 2008; Roper et al., 2014). Siblings of children with significant disabilities have been found to both be more empathetic with others, as well as feeling un- or less-loved by their parents, believing more attention is going to the child with the disability (Giallo & Gavidia-Payne, 2006; Neely-Barnes & Dia, 2008; Roper et al., 2014). Of course, this in turn could affect the way the sibling interacts with peers, teachers, or extended family members (Canary, 2008; Cox & Paley, 1997; Giallo & Gavidia-Payne, 2006). Collectively, having at least one child with a disability impacts the entire family system. In accordance with family systems theory, if one wishes to intervene systemically, one must begin by looking at the entire system (Gelkopf & Roe, 2014).

Relational Challenges in Families of Children with Disabilities

Scheduling appointments, managing transportation, and coordinating care are just a few of the tasks that parents of children with SD must complete, in addition to the regular daily tasks of bathing, feeding, and entertaining of their children and all of this is in addition to the intrapersonal meaning making being done by these parents (DHHS, 2013; Gordon, 2009; Patrick-Ott & Ladd, 2010). Often though, these parents must also fight (frequently reframed as advocating) for services for their children, adding to the daily stress they feel (Knestrict & Kuchey, 2009; Patrick-Ott & Ladd, 2010; Solomon & Chung, 2012). This extensive list is in exclusion of any work outside of the home, any other relationships (e.g., spousal, friend, extended family), or caring for any other children—let alone any self-care. It is clear to see how parents of children with SD may

report feeling more stress than families of typically developing children (Neely-Barnes & Dia, 2008; Solomon & Chung, 2012).

Finances. Approximately 22% of families (DHHS, 2013) reported that their child's condition causes them financial difficulties (Gordon, 2009; Knestrict & Kuchey, 2009; Melnyk et al., 2001). Finances have also repeatedly been shown to both be a barrier to children with SD receiving the services they need, as well as having a negative impact on marital satisfaction (Archuleta et al., 2011; DHHS, 2013; Gordon, 2009; Knestrict & Kuchey, 2009; Solomon & Chung, 2012). Increased resources (e.g., time, money, services) have repeatedly been correlated to resiliency in families with a child with significant disabilities (DHHS, 2013; Gordon, 2009; Knestrict & Kuchey, 2009; Lin, 2000; Melnyk et al., 2001; Solomon & Chung, 2012).

SES. DHHS (2013) also echoed findings of other researchers, in reporting that children from lower income families (37.5% of families in the report) needed more services than children in more affluent families (18.4%) (Knestrict & Kuchey, 2009). In these lower SES families, non-Hispanic white children were reported to be the most likely to deny consistent effects from their conditions, while Hispanics were the most likely to report being affected—even though this group (i.e., Hispanics) is the least likely to report having conditions (DHHS, 2013). In other words, while Hispanics were less likely to say they have significant disabilities, those who did report were the most likely to report being negatively or significantly affected by these disabilities.

Services. While many services may be available for school aged children, once children "age-out" of the school system, the family may be at a loss to identify services

for their now adult child (DHHS, 2013). Some of these families (12%) report a desire for family counseling to deal with their child's diagnosis (DHHS, 2013). The age group of 12-17 years is the largest group to report having children with SD, and the group with the most needs (DHHS, 2013). Additionally, boys generally need more services than girls—but this is also the largest group nearing the aging-out point (DHHS, 2013). Helping families transition their minor child to adult services is one of the needs least often met by current available services (DHHS, 2013).

In a similar fashion to the life-cycle phases that most families go through, some researchers hypothesize that families with children who have SD also go through somewhat predictable phases (Gordon, 2009; Patrick-Ott, 2011). It is further hypothesized that at these various times (e.g., during times of diagnosis, illness exacerbations, and developmental transitions), families are likely to experience increased stress levels (Gordon, 2009; Knestrict & Kuchey, 2009; Malia, 2007; Melnyk et al., 2001; Solomon & Chung, 2012). During these times, the parents may be reminded of the loss of their idealized child (Gordon, 2009; Patrick-Ott & Ladd, 2010). This resurgence of stress levels can impact all areas of the family, particularly the couple's relationship.

The reasons for marriage, and remaining married, have changed considerably (in America) over the last several decades (Campbell & Wright, 2010; Skolnick, 2007). Historically, people married for the purposes of various economic, financial, or social reasons, as well as creating and raising a family (Campbell & Wright, 2010). However, more recently, the concept of romantic love has taken over being a requirement of marriage, with each partner seeking personal fulfillment (Campbell & Wright, 2010;

Skolnick, 2007). If a couple, or one member of this couple, feels unfulfilled, in addition to the stressors of raising a child with SD, would this affect their willingness to remain in the unfulfilling marriage? It would be interesting to know if these added stressors increase the level of marital satisfaction or decrease it as has been seen in previous research (Darling et al., 2012; Patrick-Ott & Ladd, 2010; Skolnick, 2007).

Collectively, how these families use their available resources to deal with the stressors they are presented with, or how the lack of resources further contributes to stress pile-up, can impact other aspects of the family—where family stress theory and systems theory merge (Hill, 1949; Patterson & McCubbin, 1983; von Bertalanffy, 1968). The satisfaction of the marital relationship is one subsystem that can be impacted by the family system's ability to cope with the given stressors (Solomon & Chung, 2012).

Marital Satisfaction

Adding a child to a family is a stressor in itself. When the child has special needs, this stress is increased (Darling et al., 2012; Gordon, 2009; Olshansky, 1962; Patrick-Ott & Ladd, 2010; Solomon & Chung, 2012; Teel, 1991). Parents now must deal with the regular care-taking needs of their child, all the while also dealing with their own chronic sorrow, ambiguous loss, and disenfranchised grief—as well as intrapersonal needs and interpersonal needs of their relationship. Plugged into the model of family stress, these most likely fall under the "A" section, as stressors, often chronic and changeless (Hill, 1949; Patrick-Ott & Ladd, 2010; Patterson & McCubbin, 1983).

Often this stress falls on the mothers, as the primary care-takers, and is compounded when some fathers withdraw while dealing with their own ambiguous loss

process (Lawrence, Rothman, Cobb, & Bradbury, 2010; Patrick-Ott & Ladd, 2010; Solomon & Chung, 2012). Other researchers, though, have found that fathers experience increased stress like the mothers, just in different areas (e.g., providing, worrying about social acceptance of the child) (Darling et al., 2012). This extra work can add stress to the marital relationship, and can reduce the satisfaction in the relationship (Darling et al., 2012; Khazan, McHale, & Decourcey, 2008; Lawrence et al., 2010; Patrick-Ott & Ladd, 2010; Shek & Tsang, 1993; Skolnick, 2007).

Lawrence, Rothman, Cobb, and Bradbury (2010) found, with normally developing children, that changes in marital satisfaction tend to level off a few months post-partum, for parents of newborns. While the reasons are unclear, the researchers hypothesize that this is because social support levels off as the infant ages (Lawrence et al., 2010). In families with typically developing children, it is at this point that marital satisfaction may begin to decline; the work load continues, but the support diminishes. As we have seen, the work load for families with children who have special needs may never really subside or may subside only to resurge months or years later in the cases of children diagnosed later in life. Back to the family stress model, the stressors on the parents remain the same (perhaps even growing as the parents' recognition of the changelessness of their situation grows), but the resources available to the family may decline and/or become more difficult to obtain (Hill, 1949; Patrick-Ott & Ladd, 2010; Patterson & McCubbin, 1983).

As a result, the division of labor within the home becomes an important area of focus, especially as it relates to marital satisfaction, particularly for women. Lawrence et

al. (2010) reported that wives who were doing more housework and child care than they had expected to do were less satisfied with their marriage, and as one can imagine a child with SD is likely to require more work than was anticipated. It may be possible that the division of the work load that parents experienced when caring for the child with SD impacts marital satisfaction—or perhaps it is just the couple's perception of how they think the workload should be distributed (the analysis of which is beyond the scope of this study).

Overall, multiple factors have been identified that effect outcomes for individuals with SD and their families. Canary (2008) identified a negative correlation between the diagnosis (specifically the severity of a diagnosis/disability) and levels of perceived support available, as well as to marital satisfaction. Furthermore, the perceptions of helpfulness of this often informal support is associated with lower parental stress, increased feelings of parental empowerment, and increased marital satisfaction (Canary, 2008). Collectively, these components relate back to the ABC-X models developed by Hill (1949) and Patterson and McCubbin (1983), and how effects of these stressors may be mediated via resources and perceptions. Understanding what helps these couples maintain their intimate relationship is important to family science professionals, when working with families of children with SD.

Hardiness

According to McCubbin et al. (1987b), in the context of families, hardiness is closely linked to the family schema, "the basic strength families call upon to manage the hardships and difficulties of transitions and crises" and possibly may offset the illness

creating effects (p. 125). This ability to bounce back also emerges in the literature on marital satisfaction (McCubbin et al., 1997). In this context, resilience is defined as the ability to adjust "which involves the influence of protective factors in facilitating the family's ability and efforts to maintain its integrity, functioning, and fulfill developmental tasks in the face of risk factors" and adapt "which involves the function of recovery factors in promoting the family's ability to 'bounce back' and adapt in family crisis situations" (McCubbin et al., 1997, p. 4). In accord with the isomorphic nature of systemic theory, resilience in the marital relationship fosters resilience in the familial relationship, the foundation from which the children develop and thrive (McCubbin et al., 1997). Alternately, regarding hardiness, McCubbin et al. (1987b) identified regressive coping techniques as techniques that would be "characterized by the avoidance of the situation brought on by the stressor event, distracting actions, and a pessimistic appraisal of the event" (p. 127).

Applying the family stress model, one could see how resilience can be a resource that the family uses to moderate the ongoing chronic sorrow, ambiguous loss, changelessness, and other stressors resulting from caring for a child with SD (Hill, 1949; Patterson & McCubbin, 1983). Alternately, resilience may also foster the family's perception (the C of the family stress model; Hill, 1949; Patterson & McCubbin, 1983) that they are able to handle the stressors, further contributing to growing resilience. Of course, this then becomes a 'chicken or the egg' argument of which came first: Did the family already have resilience (a resource-the B factor), and as a result they were able to overcome the stressors (the A) and avert a crisis (the X) or did the stressors (the A) create

the resilience (a resource-B), which then allows the family to change their perception (the C) of the stressor (the A) as something that is overcome-able and thus avert a crisis (the X) (Hill, 1949; Patterson & McCubbin, 1983)? What factors correlate with a family's ability to navigate the stressors resulting from caring for a child with SD? As family specialists, what characteristics can we identify that may increase a family's ability to increase resilience?

Summary

Families of children with SD have stressors that families of typically developing children do not have, which can have an impact on the family functioning (Canary, 2008; Giallo & Gavidia-Payne, 2006; Gilbert et al., 2008; Gordon, 2009; Hall et al., 2012; Hill, 1949; McCubbin et al., 1997; Neely-Barnes & Dia, 2008; Olshansky, 1962; Patrick-Ott & Ladd, 2010; Patterson & McCubbin, 1983; Ray et al., 2009; Robinson & Neece, 2015; Solomon & Chung, 2012). Understanding how these various stressors impact the family is important for professionals who work with families of children with SD (Gordon, 2009; Hill, 1949; Hall et al., 2012; McCubbin & McCubbin, 1987; McCubbin et al., 1987a; McCubbin et al., 1987b; Neely-Barnes & Dia, 2008; Olshansky, 1962; Patrick-Ott & Ladd, 2010; Patterson, 1988; Patterson & McCubbin, 1983; Ray et al., 2009; Robinson & Neece, 2015; Solomon & Chung, 2012). Specifically, the meanings made by the family members have an important impact on how the family deals with the stressors (Gordon, 2009; Hall et al., 2012; Hill, 1949; McCubbin & McCubbin, 1987; McCubbin et al., 1987a; McCubbin et al., 1987b; Neely-Barnes & Dia, 2008; Olshansky, 1962; Patrick-Ott & Ladd, 2010; Patterson, 1988; Patterson & McCubbin, 1983; Ray et al.,

2009; Robinson & Neece, 2015; Solomon & Chung, 2012), and can impact various, perhaps unexpected, aspects of family functioning such as marital satisfaction (Neely-Barnes & Dia, 2008; Robinson & Neece, 2015; Solomon & Chung, 2012) and resilience (Gordon, 2009; Hall et al., 2012; Hill, 1949; McCubbin & McCubbin, 1987; McCubbin et al., 1987a; McCubbin et al., 1987b; McCubbin et al., 1997; Neely-Barnes & Dia, 2008; Patterson, 1988; Patterson & McCubbin, 1983; Robinson & Neece, 2015; Solomon & Chung, 2012). It is helpful for systemically trained family professionals to assist the family in navigating the process of caring for children with SD from the time of diagnosis throughout the life span (Gordon, 2009; Hall et al., 2012; Neely-Barnes & Dia, 2008; Ray et al., 2009; Robinson & Neece, 2015; Solomon & Chung, 2012). This mixed methods research study attempts to build upon this current literature in regard to how families of children with SD function, specifically in regard to marital satisfaction, family hardiness, family coping, and how the meaning made by the family members may affect these variables.

CHAPTER III

METHODS

According to Creswell and Plano Clark (2007), mixed methods research allows for a more holistic picture of a topic being researched. This research project is a mixed methods study which had two purposes: First, the collective research team sought to expand the qualitative themes found in Patrick-Ott's (2011) research study; and, second, to provide this author with the opportunity to complete her dissertation by gathering both quantitative and qualitative data on marital satisfaction, family coping, and hardiness as reported by parents raising a child with significant disabilities. The original project was designed where the quantitative data would belong to this researcher, and the qualitative data would belong to Patrick-Ott as it was an expansion of her original dissertation (Patrick-Ott, 2011). However, Patrick-Ott graciously granted this researcher use of a sample of her qualitative data to allow this researcher to create a more holistic, mixed methods, picture of the participant families as described by Creswell and Plano Clark (2007).

For data collection purposes, the website URL www.SpecialFamiliesSpecialStories.com was used for recruitment purposes. A mixed methods online survey was developed and posted on PsychData, via the above URL. This project received expedited review by the Texas Woman's University Institutional Review Board and received approval in July, 2013.

Procedures

Sample Recruitment and Sample

Recruitment. Using a targeted approach, participants were recruited via email and postings on various local and state websites designed specifically to serve families of children with significant special needs. In addition, researchers contacted various national organizations such as Come Unity and the National Autism Society who agreed to place a link to the study survey on their webpages (see Appendix D). Using a snowball approach, participants were invited to share the email flyer with other potential participants (see Appendix E). In addition, known caregivers in the local and regional area surrounding Dallas, Texas, were emailed information about the study and asked to share the study flyer with potential participants. Finally, the link for the study was shared via Facebook in relevant groups and pages.

Sample criteria for participants. Sample criteria were as follows: Caregivers (i.e., parent, step-parent, grandparent, adult sibling, extended family member or guardian) of children (regardless of the child's age) were invited to participate in the study if the target child had lived in the home for at least 11 months of the past year, the caregiver was over 18 years of age, and could read English at a third grade level or above. Data about the final sample is included in chapter 4.

Criteria for children with significant disabilities. There were no restrictions regarding the age of the child (i.e., the child did not need to be a minor) or type of diagnosis of the child, if it fit the definition of "significantly disabled" provided in Chapter 1, as determined by the respondent. However, participants did need access to the

internet to complete the survey; thus, an internet connection and a device to access the internet was required. Researchers hoped that participants would be of various ages, educational levels, income (socio-economic status) levels, marital statuses, and various ethnicities. It was expected that all participants would be living in the United States, but the study was not closed to people from other countries who may have accessed the survey.

Participation in the online survey. When an individual chose to participate, they accessed the internet from a device of their choosing, in a setting of their choosing, and at time of day of their choosing. Participants were able to access the link provided, which was available 24 hours a day, seven days a week until the survey was closed. The survey took approximately one hour to complete, and on the last page, a list of resources was included if a participant felt the need for counseling or support.

Participation requirements and informed consent were displayed on the first page of the online survey. The participants were asked to continue to the next page only if they met the requirements as outlined and, then, gave consent to participate. The second page of the survey included demographic questions and Dr. Ott's qualitative questions were on the third page. The fourth page of the survey included the KMSS (Schumm et al., 2008; Schumm et al., 1986), and the FHI (McCubbin et al., 1987b), with Likert scale questions while the fifth and last page of the survey included the F-COPES (McCubbin et al., 1987a).

After completing the survey, a final page of the survey thanked the participants and included a link to another survey page that the participants could click if they would

like an executive summary of the results. Both the conclusion page of the survey and the page where the participant could submit their email address for the executive summary included disclaimers about the loss of anonymity by providing their contact information. By typing in their email address, participants acknowledged and accepted this possible loss of anonymity.

Participation was anonymous unless the participants chose to provide an email address for the executive summary. Even this information, though, was kept separate from the surveys in an attempt to maintain anonymity. Participation was voluntary, and the participants could leave the survey at any time, but were not be able to save progress on a survey and resume it at a later time. This is due to the set-up of Psychdata which required a password to leave and re-enter the survey, which would have compromised the anonymity of the participant. Once a participant entered the survey, they proceeded at their own pace until they exited the survey.

PsychData Survey

Checking Sample Criteria

To participate in the survey, individuals were asked to self-determine if they met the research participant criteria as follows:

(1) Being the primary caretaker (parent, step-parent, grandparent, guardian, adult sibling, extended family member or guardian) of a child diagnosed with significant disabilities that lived in their home at least 11 months of the year;

2) Being an adult that is at least 18 years old;

3) Being able to read English (at the 3rd grade level).

Participants were asked to read and acknowledge the purpose of the study and the Informed Consent (including risks) on the first page of the survey. Progressing to the second page was considered consenting to participation in the survey. The final page of the survey offered participants a link where they were asked if they wanted to sign up for an executive summary of the study, indicate their interest in participating in future research, and provided participants with a list of community resources if desired.

Demographic Questions

Via Psychdata, this author collected basic demographic information via five questions as follows: Participant relationship to the child, participant age, participant education level, family income, and participant marital status. An additional six questions were used to gather information about the child with significant disabilities (SD) and the family composition as follows: Gender and age of child with SD, diagnosis, number of other children currently living in the home, and if the child with SD has lived in the home for 11 of the last 12 months (see Appendix B).

Qualitative Survey

The qualitative research questions listed below were based on the themes identified in Dr. Patrick-Ott's (2011) previous research. There were seven qualitative questions that focused on the experience of raising a child with significant disabilities. All questions were followed by a text box, where participants could type in their responses to the questions/prompts. These questions are presented here, with the numbers as they are found in the survey:

13) When you first realized that your child was not reaching the major developmental milestones for his/her developmental age, what was your reaction?

14) When you received the initial diagnosis for your child, what was your reaction? What process did you use to help you understand your child's diagnosis and deal with your emotions?

15) How did receiving a diagnosis for your child impact how you cared for your child on a day to day basis -- and over the years?

16) Please consider the emotional journey you have taken since the birth of your child and the diagnosis of his/her disorder. Would you say that you have experienced an "ebb and flow" of emotions? Is there a "changelessness" about your parenting of your child?

17) As a parent of a child with significant disabilities, how have you managed to care for yourself? What has helped you separate your own individuality from that of being your child's parent?

18) How has the experience of raising a child with significant disabilities changed you? How has it affected your relationship with your other children or your spouse/partner?

19) How do you see the future for yourself and your child? What plans have you made for your child when you are not able to care for him/her?

20) How has raising a child with significant disabilities impacted your relationship with friends or extended family members? How has it changed the way you

interact with the medical profession and organizations that serve children with significant disabilities?

The previous questions all had limited character text boxes after the questions; the number of characters allowed in the text box was limited (maximum characters = 1000) to encourage the participant to focus their response on the theme of the question. These guided questions were designed to focus the participants' thoughts on themes previously identified as common among families of persons with SD, by Patrick-Ott (2011). One final qualitative question was included to allow participants to expand on any previous question, or to include any other information they believed to be important: "21) It is now your turn to share your story of your family in the space below. Feel free to expand on anything you said in the specific questions above or share your thoughts or experiences about something else important in your life or in your family." The text box for this question allowed up to 28,000 characters to offer the participants to share more information as was desired.

Quantitative Measures

The research study included three quantitative instruments: The KMSS (Schumm et al., 2008; Schumm et al., 1986), the FHI (McCubbin et al., 1987b), and the F-COPES (McCubbin et al., 1987a) as well as demographic information. All quantitative data received was used for this analysis. Permission was requested, and obtained, from Schumm, author of the KMSS for its use in this project (see Appendix C). FHI and F-COPES is available in the public domain and did not require specific permission.

After reviewing risks and consenting to proceed with the survey, participants responded to demographic data questions determining the participant's relationship to the child; the age of child and participant; income and education level of participant; marital status; and the child's diagnosis. The second section of this study asked about the seven themes that Patrick-Ott (2011) found in her previous research. The three quantitative instruments follow these qualitative questions.

Measurements

Kansas Marital Satisfaction Survey

The KMSS was developed by Schumm of Kansas State University (1983). Schumm, and other researchers, have used this instrument in variable formats and repeatedly found high consistency, reliability, and validity (Crane et al., 2000; Schumm et al., 2008; Schumm et al., 1986). The self-administered questionnaire has been researched with three, five, and seven question formats, with seven possible Likert-style responses (Crane et al., 2000; Schumm et al., 2008; Schumm et al., 1986). The short version has three questions, with total possible scores between three and 21, where scores of 16 and below indicate some level of marital distress (Crane et al., 2000).

Most recently, Schumm (2008) used the survey with five and seven response formats with a sample of Army personnel. In that study,

> Cronbach's alpha for the marital instability scale was 0.81. The alpha for the five-response format KMSS (N = 81) was 0.96. Cronbach's (1951) alpha for the seven-response format KMSS (N = 73) was 0.98. In terms of validity, the marital instability scale was substantially and significantly

> correlated with both the five-response format KMSS (r = -0.88, p <.001) and with the seven-response format KMSS (r = -0.82, p < .001), using the Pearson zero-order correlation (two-tailed). The correlations remained significant using the nonparametric Spearman rho (-0.81, p < .001 and -0.75, p < .001, respectively) (Schumm et al., 2008, p. 31).

Shek and Tsang (1993) translated and used the three question version of the KMSS, called the C-KMSS with a sample of Chinese parents raising a child with metal disabilities, and also found it to be reliable (Cronbach's alpha=.92).

For this current project, the three-question format was used, with a possible total composite score of 21. Scores of less than 16 were considered indicative of marital distress, as outlined in Crane, Middleton, and Bean (2000). Respondents who are not in a relationship were asked to skip these questions, resulting in missing data on this instrument, as expected. For this study, Cronbach's alpha was .97.

Family Hardiness Index

The FHI, developed by Marilyn McCubbin, Hamilton McCubbin, and Anne Thompson (1987b), was designed to measure the

> characteristic of hardiness as a stress resistance and adaptation resource in families which would function as a buffer or mediating factor in mitigating the effects of stressors and demands, and a facilitation of family adjustment and adaptation over time. Family hardiness specifically refers to the internal strengths and durability of the family unit and is characterized by a sense of control over the outcomes of life events and

> hardships, a view of change as beneficial and growth producing, and an active rather than passive orientation in adjusting to and managing stressful situations (p. 125).

The FHI was designed to adjust the concept of individual hardiness to the family group, and incorporates the three concepts of commitment, challenge, and control, from a "we" perspective (McCubbin et al., 1987b, p 125). The focus during the development of the FHI was on how families approached the hardships of life and how they typically perceived the impact of these events and how they changed the functioning of the family (McCubbin et al., 1987b, p. 125). When applied to the family, four interrelated components were identified, which were then used as a base for the development of the four subscales of the FHI (McCubbin et al., 1987b, p. 125). These include: (a) co-oriented commitment, a focus on how the family works together to manage difficulties; (b) confidence, the family's belief in being able to handle their own problems; (c) challenge, which focuses on the family's emphasis on viewing hardships as a challenge and seeking of new life experiences as challenges; and (d) control, a focus of an internal sense of control rather than being the victim of circumstances (McCubbin et al., 1987b, p. 125). With its emphasis on family functioning, as opposed to individual functioning, this instrument fits well with the research questions posed here within.

The FHI is a self-administered 20-item, Likert style (four response options), ranging from 0 (completely false) to 3 (completely true) instrument, designed to measure the participant's perception of the family's patterned response to the hardships of life (defined by the authors as hardiness) (Ahlert & Greeff, 2012; Nabors et al., 2013). A total

score could then be calculated, from all subscales, with total scores range from 0-60, where higher scores indicate greater family hardiness (Nabors et al., 2013). Mean scores can also be used to compare families to themselves over time, as well as to other families (McCubbin et al., 1987b). The overall internal reliability (Cronbach's alpha) of this scale is .82 (McCubbin et al., 1987b; Greeff & Nolting, 2013).

The internal reliability for the total FHI score for Kapp and Brown's (2011) sample was r = .40 and the subscales were r = .75 (commitment), r = .73 (challenge) and r = .67 (control). Ahlert and Greeff (2012) reported internal reliability (Cronbach's alpha) of the total scale to be r = .46*;* the challenge subscale was .56, the control subscale .64, and for the commitment subscale .61. In a later study, Greeff and Nolting (2013) obtained an overall internal reliability (Cronbach's alpha) of .59, with an internal reliability of .62 for the commitment subscale, .58 for the challenge subscale, and .74 for the control subscale. Cronbach's alpha, totaled for all subscales, for this study was .94. Interestingly, Greeff and Nolting (2013) also found a significant positive correlation between family adaptation (as measured by the Family Attachment and Changeability Index) and the scores obtained on the commitment and challenge subscales of the FHI. Nabors et al. (2013) went on to say that the internal strengths and durability of the family, measured by the FHI, can be thought of as a "resilience factor" (p. 174).

A total score for this instrument was used, and then compared to total scores on other instruments. For participants who began the assessment, but did not complete the entire assessment, imputed data was used, as suggested by a statistician on the committee for this project (D. Marshall, personal communication, Nov. 27, 2017). An average for

the item was used in the place of missing data for any participant who was missing less than 10% of the responses but responded to all other items on all three quantitative assessments.

F-COPES

The F-COPES (McCubbin et al., 1987a) draws upon the coping dimensions of the resiliency model of family adjustment and adaptation in which the following factors are integrated: Pile-up, family resources, and meaning/perception, which themselves specifically draw upon the double ABC-X model (p. 195). The F-COPES "were created to identify problem solving and behavioral strategies used by families in difficult or problematic situations" (McCubbin et al., 1987a, p. 195). Thus, the instrument includes 30 coping behavior items which focus on the two levels of interaction outlined in the resiliency model: "(1) individual to family system, or the ways a family internally handles difficulties and problems between its members; and (2) family to social environment, or the ways in which the family externally handles problems or demands that emerge outside its boundaries, but affect the family unit and its members" (McCubbin et al., 1987a, p. 195).

It was hypothesized that families operating with more coping behaviors focused on both levels of interaction will adapt to stressful situations more successfully (McCubbin et al., 1987a); the F-COPES considers problem solving and coping behaviors (Blucker, Elliott, Warren, & Warren, 2011; Greeff & Nolting, 2013; Kapp & Brown, 2011; Morse, Rojahn, & Smith, 2014). Internal coping patterns included the way individual family members handled difficulties by using resources residing within the

family system, while external coping patterns were when family members actively sought and used resources from outside the nuclear family system (McCubbin et al., 1987a, p. 196).

The F-COPES 30 items are in Likert response style (responses range from 1 (strongly disagree) to 5 (strongly agree), self-administered questionnaire that measures internal and external responses to stress (i.e., coping patterns) (McCubbin et al., 1987a). Subscales include: a) social support seeking, b) cognitive reframing, c) spiritual support seeking, d) acquiring and accepting help, and e) passive appraisal. A "score" can be obtained from the results collectively and on individual subscales (Blucker et al., 2011; Kapp & Brown, 2011; McCubbin et al., 1987a; Morse et al., 2014). Overall, Cronbach (1951) alpha levels range from 0.71 to 0.86, and test-retest reliability coefficients range from 0.61 to 0.95 (Blucker et al., 2011; Kieckhefer et al., 2014; Morse et al., 2014). The F-COPES has a test-retest reliability of .71 and an internal reliability coefficient of .77 (Cronbach alpha) as reported in the literature (Kapp & Brown, 2011). Like the FHI, mean scores can also be used to compare families to themselves over time, as well as to other families (McCubbin et al., 1987a).

In Kapp and Brown's (2011) study, the internal reliability for the subscales were: (1) acquiring social support (.84), (2) reframing (.82), (3) seeking spiritual support (.89), (4) mobilizing family to acquire and accept help (.52), and (5) passive appraisal (.56). In Darling, Senatore, and Strachan's (2012) article, the internal coping measurement scale had a Cronbach's alpha of .75 and external scale had a Cronbach's alpha of .85 and a reliability score of .87. In their use of F-COPES, Greeff and Nolting (2013) reported an

internal reliability (Cronbach's alpha) of .63 on the reframing subscale, .61 on the passive appraisal subscale, .76 on the social support subscale, .52 on the religion and spirituality subscale, and .60 on the mobilization subscale. The scale has an overall internal reliability (Cronbach's alpha) of .77 (.63-.83 for the subscales) and a test–retest reliability of .81 (.61 to. 95 for the subscales) (Blucker et al., 2011; Greeff & Nolting, 2013).

In this current study, a total score for F-COPES was used, and then compared to the total scores from the other two instruments, KMSS and FHI. For participants who began the assessment, but did not complete the entire assessment, imputed data was used. An average for the item was substituted in the place of missing data for any participant who was missing less than ten percent of the responses but responded to all other items on all three quantitative assessments, as suggested by a statistician on the committee for this project (D. Marshall, personal communication, Nov. 27, 2017). In this study, Cronbach's alpha was .83, total, for all subscales.

Study Variables and Statistical Analysis

The expectation was to have families from a variety of income and educational levels, as well as various marital statuses, participate in the study. It was hoped that the demographics of participants would be similar to those found in the research by the DHHS (2013) and the ACS (USCB 2016a, 2016b) of families of children with SD. Demographic questions were analyzed using analysis of variance (ANOVA), correlations, and t-tests.

The three quantitative instruments (KMSS, FHI, and F-COPES) all use Likert scales, where a "total score' for each instrument can be obtained; therefore analysis of

variance (ANOVA) was used to look for interactions. Pearson's correlations were also ran to determine any relationships between the instruments, demographic information, and meaning made of the child's diagnosis by participants. A linear regression was also looked at to determine any relationships between the variables.

Qualitative Data

The goal of combining a small sample of the qualitative data with the quantitative data was to attempt to produce the more 'complete picture' of the families studied, via a mixed methods research design as described by Creswell and Plano Clark (2007). In her dissertation, Patrick-Ott (2011) interviewed eight parents as a pilot study using a grounded theoretical design which yielded seven preliminary themes that described a developmental timeline for how those eight parents raised children with disabilities, highlighting the effect that raising a child with SD had on the family as well as the meaning the respondents made of these challenges. As this current study was designed to confirm and expand Patrick-Ott's previous qualitative research (e.g., Patrick-Ott, 2011), phenomenological theory was the most appropriate lens (Black & Enos, 1981).

Phenomenological theory addresses both the systemic aspect of knowledge, as well as the intrapersonal aspects, with a strong emphasis of the meanings assigned to the words and phrases used by the speaker (Black & Enos, 1981). As the concept of a disability is going to be based on social constructions of what is considered normal, a theory that addresses respondent's stories from a systemic perspective is important. However, this study focuses on the effect this disability has on the family, thus a theory

that looks at things from an individual perspective, specifically the meanings made by these individuals, would be important as well.

According to Durkheim (1938), these meanings are strongly influenced by the speaker's beliefs, values, norms, attitudes, and opinions which are strongly influenced by the speaker's experiences which have been learned and internalized by the speaker. Phenomenological theory allows for analysis from both perspectives (Black & Enos, 1981). As Patrick-Ott worked to establish the theoretical blending of chronic sorrow (Olshansky, 1962) and ambiguous loss (Boss, 2006), it would be appropriate to then tie the data acquired in this study to the data she previously acquired. Phenomenological theory would be appropriate for building on this groundwork (Black & Enos, 1981).

Summary

Mixed methods research allows for a more holistic picture of the issue being researched than either qualitative or quantitative research alone, to the point that Creswell and Plano Clark (2007) stated "they need to be mixed together…so that they form a more complete picture of the problem than they do when standing alone" (p. 7). This mixed methods research project analyzes data about the experiences of care-takers of children with significant disabilities, with the purpose of viewing this picture through an ABC-X theoretical lens (Hill, 1949; Patterson & McCubbin, 1983).

CHAPTER IV

RESULTS

The purpose of this online mixed methods study was to expand researcher and educator understanding of the experience of caregivers raising children living their home who had been diagnosed with severe disabilities. In this study, caregivers were asked to complete a demographic survey plus three quantitative instruments: The KMSS (Schumm et al., 2008), the FHI (McCubbin et al., 1987b), and the F-COPES (McCubbin et al., 1987a). Besides gathering demographic data, this researcher also asked the caregivers to complete nine qualitative questions replicated from Patrick-Ott's dissertation study (2011) that piloted an exploration of how parents cope with raising a child with significant disabilities across time. This chapter reports on the results of both the qualitative and quantitative data gathered in this study.

Participants

A total of 70 respondents began the survey, but after removing duplicates and incomplete responses, 68 participants remained. To consider the quantitative hypotheses, that number of 68 respondents was reduced to 38 adult caregivers (55.8%) who completed the quantitative and qualitative sections of the survey. Those caregivers not in a relationship did not complete the KMSS but were included in this group of 38 named Group 1. Quota sampling was used to derive Group 2 (10 respondents) from Group 1 for the purpose of coding their qualitative data (Gliner et al., 2017). Descriptive statistics follow for each of these three groups.

Demographic Statistics on the 68 Respondents

The demographics for the overall sample of 68 caregivers are included in this section for two reasons. First, this group reports on the multiple diagnoses received by their children, which forms a backdrop for the experience of all respondents. Second, while this researcher reports on the qualitative experience of only 10 respondents, this the entire group of 68 respondents is integral to their experience.

Caregiver relationship to child with significant disabilities. Of the 68 respondents, 60 (88%) identified as the mother figure (mother, stepmother, and adoptive mother). The remaining relationships were reported as follows: Three respondents (4%) reported being the father, stepfather, or adoptive father; two respondents (3%) reported being an adult sibling; two respondents (2%) reported being grandparents; and one respondent reported being an extended family member.

Age of respondents in the original sample. Twelve respondents (17.6%) reported being in the 18-20 age category, 24 (35.3%) in the 21-30 age category, 21 (30.9%) in the 31-40 age category, 9 (13.2%) in the 41-50 age category, and one each in the 51-60 (1.5%), and 70+ (1.5%) age categories.

Relationship status of the 68 respondents. Of the 68 respondents, the largest group of 50 (73.5%) reported being in a committed relationship; nine (13.2%) reported being divorced; seven (10.3%) reported being single; one (1.5%) reported being widowed; and one did not answer this question.

Educational level of 68 respondents. Fourteen (20.6%) respondents reported having a high school education or GED, 20 (29.4%) reported having a two-year degree or equivalent (e.g., trade school). Seventeen (25%) respondents reported having a bachelor's degree, while 12 (17.6%) reported having a master's degree and five reported "other" (e.g., some college, J.D., Ph.D.).

Income levels of 68 respondents. Income levels were reported in ranges from less than $25,000 to over $200,000. Of the original group of 68 caregivers, 20 (29.4%) participants reported annual household incomes of $25,000 or less, while 13 (19.1%) reported incomes between $26,000-$50,000. Thirteen (19.1%) participants reported incomes between $50,001-$75,000, while 12 (17.6%) reported incomes between $75,001-$100,000. Five (7.4%) participants reported incomes between $100,001-$150,000, two (2.9%) reported incomes of $150,001-$200,000, and two (2.9%) reported incomes of $200,001 and above.

Children with significant disabilities as reported by original group. The majority of the children in the original group of 68 caregivers were male (n = 51, 75%) with 17 females (25%). In the demographic survey, there was no age limit for the age of the child with significant disabilities, therefore, the study included parents and other caregivers. The ages of all 68 children ranged from one to 80, the "child" who was 80 was dropped from further analysis. The ages of the remaining children (n = 67) are as follows: Birth to 10 years (n = 34, 50.7%), 11 to 21 years (n = 27, 40.3%), and 22 to 31 years (n = 6, 9%).

Group 1 Quantitative (*n* = 38)

The quantitative group, group 1, were all respondents who identified as the mother, stepmother, or adoptive mother role (*n* = 38, hereafter shortened to 'mother'). Six (15.8%) of their reported ages were in the 18-20 range; 11 (28.9%) in the 21-30 range; 16 (42.1%) in the 31-40 age range; and five (13.2%) in the 41-50 age range. One woman (2.6%) reported being single; 32 (84.2%) reported being in a committed relationship; four (10.5%) identified as being separated or divorced; and one (2.6%) reported being a widow. For education, four (10.5%) reported a high school level education or a GED. Thirteen (34.2%) reported a two-year degree; 12 (31.6%) reported holding a bachelor's degree; seven (18.4%) reported having a master's degree; and, two (5.3%) reported "Other" (i.e., some college).

Income levels for the quantitative Group 1 (*n* = 38) were reported as follows: Nine (23.7%) participants who reported annual household incomes of $25,000 or less and eight (21.1%) reported incomes between $26,000-$50,000. Five women (13.2%) reported incomes between $50,001-$75,000, and nine (23.7%) reported incomes between $75,001-$100,000. Five (13.2%) participants reported incomes between $100,001-$150,000; one (2.6%) reported incomes of $150,001-$200,000; and, one (2.6%) reported an income of more than $200,000. Table 1 shows the demographic data for the caregivers for both Groups 1 and 2.

The majority of the children in Group 1, were male (*n* = 28, 73.7%), and the children in this group ranged from one to 31, with the average age of 10.4 years old. Most

of these mothers reported other children in the home (*n* = 23, 60.5%), with the number of other children ranging up to four.

Table 1
Table 1 Caregiver Demographics of Groups 1 and 2

	Group 1 Quantitative (*n* = 38)			**Group 2 Qualitative (*n* = 10)**	
		n	**%**	***N***	**%**
Respondent's Age	18-20	6	16%	1	10%
	21-30	11	29%	4	40%
	31-40	16	42%	4	40%
	41-50	5	13%	1	10%
Marital Status	Single*	1	3%		
	Married*	32	84%	9	90%
	Separated*	4	11%	1	10%
	Widowed	1	3%		
Education Level	High School*	4	11%		
	2-year Degree*	13	34%	4	40%
	4-year Degree	12	32%	3	30%
	Master's Degree	7	18%	1	10%
	Other (some college)	2	5%	2	20%

	Group 1 Quantitative (*n* = 38)			Group 2 Qualitative (*n* = 10)	
Income*		***n***	**%**	**n**	**%**
	$26,000-$50,000	8	21%	3	30%
	$50,001-$75,000	5	13%	1	10%
	$75,001-$100,000	9	24%	4	40%
	$100,001-$150,000	5	13%	1	10%
	$150,001-$200,000	1	3%		
	>$200,001	1	3%		

Qualitative Group 2 (*n* = 10)

Since the qualitative group of 10 respondents was drawn from the quantitative group of 38, all 10 participants in this group also identified as women and mothers. Their ages were one (10%) in the 18-20 range, four (40%) in the 21-30 range, four (40%) in the 31-40 age range, and one (10%) in the 41-50 age range. In this range, nine women (90%) reported being in a committed relationship, and one (10%) identified as being separated or divorced. For education, four (40%) reported a two-year degree three (30%) reported holding a bachelor's degree; one (10%) reporting having a master's degree; and two (20%) reported "Other" (i.e., having some college). Income levels for the qualitative group of 10 respondents were one (10%) participant reported an annual household income of $25,000 or less and three (30%) reported incomes between $26,000-$50,000. One woman (10%) reported an income between $50,001-$75,000; four (40%) reported

incomes between $75,001-$100,000; and one (10%) participant reported an income between $100,001-$150,000. See Table 1 for comparison of caregiver demographics with Group 1 (the quantitative group).

The majority of the children in group 2 were male (*n* = 7, 70%), and the children in this group ranged from one to 22, with an average age of 11.2 years. Most of these mothers reported other children in the home (*n* = 6, 60%), with the number of other children ranging up to three.

Qualitative Data

Multiple Diagnoses

The original group of 68 respondents reported a total of 274 diagnoses, an average of just over four diagnoses per person, with a range of one diagnosis to 14 diagnoses per child. For example, Respondent 4 reported 13 different diagnoses over the course of their child's life:

> Pre-term birth, tracheomalacia, Laryngomalacia, stenosis, bronchopulmonary dysplasia, hepatoblastoma, failure to thrive, moderate to serve hearing loss, portal hypertension, oral aversion, bi-lateral vocal cord paralysis, ADHD, sensory process disorder, [and] developmental delays.

Another caregiver, Respondent 28 reported the following about their child (age six) at the time of the survey:

> My son was born @ 27 weeks 6 days due to premature labor that lab tests could find no reason for at all. Resolved: Respiratory distress 2x, low birth

> weight, prematurity, congestive heart failure, PDA ligation, 2 holes in his lung, chest tub to inflate lungs, ventilated twice due to respiratory arrest, on oxygen frequently, Cholestatic jaundice from the TPN resolved approximately 6 mos. with medication, anemia resolved with 8 blood transfusions, & his last major illness was sepsis plus necrotizing enterocolitis. GERD with choking on reflux resolved around 1 yr. Retinopathy of prematurity & astigmatism resolved by 1. Involved in NIGRADS study @ the Child Study Center-Fort Worth following preemies to 3 y/o with testing every 3-6 mos. Speech at 1 regressed to not speaking. Speech delay, nonverbal with severe language disorder. At 2.5 he was dxd PDD-NOS, at 3 dxd classic autism, SIB, conduct disorder, encephalopathy, chronic constipation, encopresis, and sensory issues. (sic)

A review of the other diagnoses (see Appendix F) demonstrates an overlap in how professionals evaluated the children. For example, several respondents reported that their child was diagnosed with both ADD and ADHD; another caregiver reported that their child was diagnosed with "developmental delay with autistic tendencies [and, later] Autism." The reported total of 274 diagnoses could illustrate the difficulty of diagnosing young children or may represent some other inaccuracies that will be discussed in the final chapter.

ICD 10-CM Categories

The 274 diagnoses reported by the original group of 68 caregivers were grouped into ICD 10-CM codes (U.S. Centers for Medicare & Medicaid Services [CMS], (2017),

but two diagnoses could not be grouped and were dropped. The final group of 272 diagnoses were coded into 17 categories (see Table 2).

The majority of the 272 disorders (*n* = 219) fell into four ICD 10 - CM categories: F (*n* = 158), G (*n* = 23), Q (*n* = 25), and P (*n* = 13). Category F (*n* = 158) includes mental, behavioral, and neurodevelopmental disorders such as mood disorders, developmental disorders, and intellectual disabilities, including autism spectrum disorders. Category G (*n* = 23) includes diseases of the nervous system such as cerebral palsy and epilepsy. Category Q (*n* = 25) includes diagnoses in areas such as congenital malformations and chromosomal deformities. Category P (*n* = 13) is related to Category Q and includes issues related to premature births (CMS, 2017).

Table 2

List of Diagnoses Reported by Participants by ICD 10-CM Categories

ICD 10 -CM Letter Group	ICD -CM Category	*n* =
A	Certain infectious and parasitic diseases	1
C	Neoplasms	1
D	Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism	1
E	Endocrine, nutritional and metabolic diseases	2
F	Mental, Behavioral and Neurodevelopmental disorders	158
G	Diseases of the nervous system	27

ICD 10 -CM Letter Group	ICD -CM Category	*n* =
H	Diseases of the ear and mastoid process & Diseases of the eye and adnexa	10
I	Diseases of the circulatory system	3
J	Diseases of the respiratory system	3
K	Diseases of the digestive system	11
L	Diseases of the skin and subcutaneous tissue	1
M	Diseases of the musculoskeletal system and connective tissue	3
P	Certain conditions originating in the perinatal period	13
Q	Congenital malformations, deformations and chromosomal abnormalities	26
R	Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified	9
S	Injury, poisoning and certain other consequences of external causes	1
Z	Factors influencing health status and contact with health services	2

According to the Center for Medicare and Medicaid Services (CMS, 2017), Category F includes 11 different groups of diagnoses, most of which are also included in the Diagnostic and Statistical Manual of Mental Disorders (APA, 2013). Codes in this category include mental disorders such as schizophrenia, anxiety, mood or affective disorders, and developmental disorders such as intellectual disabilities and pervasive childhood disorders (CMS, 2017). Of these sections, eight were represented in this sample and are shown in Table 3 along with samples of the actual diagnoses provided by respondents.

As shown in Table 3, a total of 46 (67.6%) of the 158 participants who reported diagnoses in Category F stated that their child had been given a diagnosis of some form of ASD. The next largest diagnostic group in Category F was for attention deficit disorder or attention deficit hyperactivity disorder (ADD/ADHD, n = 24, 9%). Single diagnoses were the exception in this sample; the majority of caregivers reported multiple co-morbid diagnoses, only eight (11.8%) of respondents reported only one diagnosis for their child. However, this researcher suspects this may be due to the phrasing of the question, which will be further discussed in the final chapter.

Table 3

ICD 10-CM Diagnoses for Category F

ICD Number	ICD Category	*n* =	Examples of Diagnoses Provided by Respondent
F10-F19	Mental and behavioral disorders due to psychoactive substance use	*n* = 1	Drug Addict
F20-F29	Schizophrenia, schizotypal, delusional, and other non-mood psychotic disorders	*n* = 6	Schizophrenia; Schizoaffective Disorder
F30-F39	Mood [affective] disorders	*n* = 5	Depression; Bipolar; Mood Disorder NOS
F40-F48	Anxiety, dissociative, stress-related, somatoform and other nonpsychotic mental disorders	*n* = 14	General/Anxiety Disorder, Obsessive Compulsive Disorder
F60-F69	Disorders of adult personality and behavior	*n* = 1	Schizoid Disorder
F70-F79	Intellectual disabilities	*n* = 15	Intellectual Disability; Cognitive Delays; Learning Disabilities;

ICD Number	ICD Category	*n* =	Examples of Diagnoses Provided by Respondent
			Mentally Challenge/Mentally Retarded
F80-F89	Pervasive and specific developmental disorders	*n* = 80	Language Disorders; Nonverbal; Expressive-Receptive Language Disorders *n* = 7 Sensory Processing Disorder *n* = 8 Autism; Autism spectrum disorder' Autistic *n* =46 Pervasive/General Developmental Delays *n* = 19
F90-F98	Behavioral and emotional disorders with onset usually occurring in childhood and adolescence	*n* = 36	ADD/ADHD *n* = 24 Conduct Disorder; Oppositional Defiance Disorder; Behavior Problems' Pica *n* = 9 Tourette syndrome *n* = 3

Coding of the Qualitative Data from Ten Participants

A quota sample of ten caregivers was chosen from the 38 participants who completed all quantitative and qualitative questions on the online survey. The goal of this researcher was to code the qualitative data provided by these ten caregivers to learn whether their responses yielded a positive or a negative meaning for their experience with the intent of formulating a more holistic picture of these families (Creswell, & Plano Clark, 2007; Gliner et al., 2017).

To generate the sample of 10 caregivers, 12 random numbers were selected from the website Random.com and used to select 10 caregivers. The procedure for selecting the 10 caregivers for Group 2 followed two strategies. First, if the participant identified by the random number had completed all of the interview questions, that respondent was placed in Group 2. Second, if the participant randomly selected did not meet criteria, the participant above and then below that number was screened for whether they had completed all survey questions. If yes, one was selected. If no, this researcher used the alternate random number to identify a new participant. If both alternate participants did not meet criteria, then one of the extra random numbers was used. This process continued until 10 participants who had completed all items in the survey were selected.

To ensure that the smaller group of 10 was representative of the larger group of 38 caregivers, a t-test was run to determine differences on the remaining members of Group 1 (n = 28) and Group 2 (n = 10). No statistically significant differences were observed on any of the three instruments for the two groups. See Table 4 for more information.

Table 4

T-Test for Groups 1 and 2

		N	Mean	SD	T	df	Sig. (2-tailed)
FHI Total					-0.89	36	0.379
	Group 1	28	41.8679	12.10785			
	Group 2	10	45.6000	8.78382			
F-COPES Total					-0.577	36	0.567
	Group 1	28	89.8093	15.06541			
	Group 2	10	92.8400	11.47705			
KMSS Total					-1.294	32	0.205
	Group 1	24	13.2500	5.75779			
	Group 2	10	16.0000	5.35413			

Coding strategies. In the family stress models, the perception/meaning made by an individual of their stressor is relevant to the outcome of either a state of stress or a state of crisis, and in the double ABC-X model, these stressors can build up over time (McCubbin & McCubbin, 1987; Patterson & McCubbin, 1983). The qualitative questions answered by these 10 selected participants were coded to determine if the overall perception of the family's experience, made by the respondent, appeared to be more positive or negative as described by the ABC-X model. The qualitative answers were reviewed, initially as a whole from each participant to determine if the respondent seemed

to have an overall positive or a negative perception of their experience of raising a child with a SD (Creswell & Plano Clark, 2007). For example, in the responses of a participant whose overall outlook of the diagnosis was positive, answers to questions included the participant (and often spouses) being proactive (i.e., researching treatment, providers, medications, etc.) and often included concepts such as “being allowed” to learn or do more. For example, respondent 19 stated that the experience of raising a child with a significant disability “has allowed me to love more and not wait to express the way I feel.”

For responses that seemed unclear, the two coders identified, counted, and then summed the number of emotionally charged key words/phrases across the seven themed questions for each respondent. For example, Respondent 51, the mother of a young female, when asked about the ebb and flow of emotions and the changelessness of their situation, reported the following:

> I often feel that we were both **cheated**. I **always wanted** a little girl to do all of those mother-daughter things like girl days, shopping, cute shoes, matching outfits, etc. **She cannot** wear all of the cute shoes because she falls. She doesn't always understand what's happening around her so **we don't have** all of the cute inside jokes a mother would have with her 6 year old. Some days I **let it get me down and I just cry**. Other days I am just fine. **It hurts me** that she's different. I **always worry** about bullying, her being made fun of, or **her disappointment at not being able to do** things the "normal" kids do. For instance, **she cannot** play on the big playground equipment because her motor skills are delayed.

The bolded words were identified as emotionally charged words and were counted when the overall response of the respondent was unclear; a simple majority of the negative/positive responses yielded the coders' final decision about the respondent's perception of the family's experience of having a child with a disability.

Coding the Theme of Perception

The primary researcher identified seven of the ten responses to be positive, overall. Three of these seven required a counting of identified key phrases, as described above. The dissertation chair for this project served as the second coder, who identified four overall responses as positive, with agreement on half of the overall responses. Together, both coders reviewed responses for the participants upon which they disagreed, in order to come to a consensus (Creswell & Plano Clark, 2007). After discussion, both reviewers agreed that overall, four of the respondents appear to have a positive outlook on their child's diagnosis, while six appeared to have negative perceptions on the diagnoses. In conclusion, 60% of the respondents were identified as having a negative perception of their experience of raising a child with a SD.

The Process of How Respondents Viewed Their Family's Life Course

Coding the qualitative data across the nine questions for each of the 10 respondents yielded information that supported the process outlined in the double ABC-X model as respondents described their child's diagnoses and the subsequent impact of raising a child with a disability over time. McCubbin et al. (1987b), even reported that previous research had found that a family's coping strategy "is not created in a single instant, but is progressively modified over time" which appeared to hold true with this study (p. 195).

In the survey, the opening two questions focused on issues related to how the early stages of recognizing how the family might possibly be in Holland instead of Italy, and the impact this had on the family's life early on in the diagnosis process. The third question shifted the focus to how the family managed change from the time of the initial diagnosis to the current functioning of the family. The final five questions focused respondents on the future by asking about planning for the child's future.

Early Stages of the Diagnosis

Across all ten coded respondents, the first question about their child not reaching major developmental milestones for his/her developmental age received mainly responses that centered on negative emotionally charged words (as coded via the process discussed above). Words such as scared, worried, upset, shock, and anxious were common. However, a few respondents reported that they had reported concerns about their child's development but were dismissed by the medical professionals.

For example, Respondent 14, who is in the 21-30 age range, and is a married mother of a 14-year-old male, reported "I tried to have him evaluated starting with [a] pediatrician. Back in 1996, I was laughed at and told he's a boy they can develop slower." A second mother (#42), of a 13-year-old male, reported "My reaction was that something was wrong. I went to the doctor, but they kept telling me that it was normal to be somewhat delayed." In total, three of the 10 mothers (30%) reported they had expressed concerns about their child's development to a medical professional and had been told delays were normal. The third mother (#51), of a six-year-old female, even expressed thoughts of self-blame.

> I think I knew deep down that she was behind, but the doctors kept telling me babies meet different milestones at their own pace. I had 2 children before my daughter and they did not show these delays. At first, I just stayed positive hoping the pediatrician was correct, but in the back of my mind I knew, and I was upset about it. I blamed myself, I reached for answers that I couldn't find.

The second qualitative question focused on the experience related to hearing an initial diagnosis. One married mother (#17) in the 31-40 age range reported:

> I was in shock. I was angry, in denial, sad. These three emotions and many more fluctuated depending on the day's events. I researched autism online to learn more about it. I contacted the local Parents Helping Parents organization to learn more about autism and what services were available. I did not deal well with my emotions. I became very depressed and gained weight. I was overwhelmed. My [Significant Other] and I attempted to attend a group meeting of parents of children diagnosed with ASD. It was incredibly disheartening. All the participants were fatigued, sad, angry, and the majority were single parents after divorcing due to marital stress.

Changelessness. Later questions guided the caregivers into Olshansky's notion of changelessness. Parents were asked, specifically, about feelings of "changelessness" and the emotional process of raising a child with significant disabilities (Olshansky, 1962; Patrick-Ott, 2011; Patrick-Ott & Ladd, 2010). Two mothers referred to the experience as a

bad rollercoaster ride in this question specifically, however this word was used by many respondents throughout their narratives. Respondent 42, mother of a 13-year-old male, reported: “My emotions are all over the place. There are days that I still cry. Every day I worry about what is gonna happen with him. Is he going to 'outgrow' this? Will he live on his own? I just want him ok.” Another mother (#66), of a six-year-old female, stated “There are ebbs and flows. You take two steps forward and then three steps back.”

The final question asked how the parents’ relationships had changed throughout this process. Surprisingly, eight of the ten respondents reported strained relationships with either family, friends, or both. Two mothers reported they had “lost friends” as a result of their child’s diagnosis, while an additional two mothers mentioned only having one to two friends. Three of the respondents mentioned questioning what was said by medical professionals. One married mother (#34) in the 31-40 age range, with a college degree and an above average income, reported:

> It has changed everything in my life! Friends and extended family members who do not respect his diagnosis and see it as just a rude child or a blanket to hide the monster I have created have slowly disappeared from my life by my own wishes. It is the sad ugly truth.

Positive Perceptions of Negative Situations

However, even though the majority of the respondents were deemed by the researchers to have a negative perception of their child’s disability, not all comments were negative. One mother (#17) wrote this in the final text box:

> Although having my son was NOT a mistake, I often think of how life would be had I chose abortion…Many years lost from not taking vacations, holidays, family outings or just plain relaxing time at home. That was never the case while raising my son! The sad ugly truth is many times I wanted to run away from home because of him. I would often daydream of how easier life would be without him and my girls would also make comments throughout his life that they wished I had just had them...

Quantitative Data

Quantitative Instruments

This researcher chose three instruments for this online mixed methods study in order to assess family functioning in families providing care for a child (of any age) with a significant disability: The KMSS (Schumm et al., 2008), the FHI (McCubbin, et al., 1987b), and the F-COPES (McCubbin et al., 1987a). IBM's SPSS 25 was used to analyze the quantitative data. The FHI measurement required that nine items be reverse coded, and the F-COPES required that three items be reverse coded, so this adjustment was made in SPSS (McCubbin et al., 1987a; McCubbin et al., 1987b). This researcher worked with two different statisticians to analyze the data. Initially the statistician on the dissertation committee assisted, but when the research questions were revised, a second statistician assisted, who was later added to the dissertation committee.

Data cleanup. Prior to analysis, the data was pre-screened for missing data and outliers as some participants did not complete all three quantitative instruments. Average scores were calculated and used (i.e., imputed), as needed, for missing individual

quantitative survey questions. Very little data was missing, so this researcher was advised by a dissertation committee member to impute average scores for the missing data. Consequently, one imputed score was computed and added to each of the following variables: F-COPES (2 scores were replaced, FHI [one score], KMSS [one score], and annual income [one score]) (D. Marshall, personal communication, Nov. 27, 2017). One respondent (45) was removed Group 1, but left in the overall data set, due to more than five missing quantitative responses.

Quantitative Results

Quantitative statistics were run on the three hypotheses using the group of 38 caregivers. A smaller than expected sample size limited the types of analyses that could be run. Therefore, the statisticians on the committee approved running a single correlation table (see Table 5) for Hypotheses one through three. Finally, *t*-tests and an ANOVA were also ran to look for interactions between variables.

Findings. Of the Group 1 participants, 34 completed the KMSS, and 38 completed the FHI and the F-COPES. Total scores for the FHI, F-COPES, and KMSS were compared to demographic variables, and to each other. The correlation of the KMSS and Marital Status (e.g., a dummy code of 1 = married, and 0 = other/not in relationship) was significant (r = .403, p = .018). Therefore, when relationship status is compared with marital satisfaction, the status of being in a committed relationship (e.g., married) was significantly correlated with marital satisfaction. See Table 5 for more information.

Null Hypotheses

Ho1: There will be no statistically significant difference/relationship when total scores on two instruments, marital satisfaction (KMSS) and family coping (F-COPES), are compared with marital status, income, age, and educational level of respondent, and age and gender of the child. This null hypothesis was rejected, as a significant correlation between the total scores on the KMSS and the total scores on the F-COPES was identified (r = .437, p = .010). No other variables were significantly correlated in this analysis.

Ho2: There will be no statistically significant difference/relationship when total scores on two instruments, marital satisfaction (KMSS) and family hardiness (FHI), are compared with marital status, income, age, and educational level of respondent, and age and gender of the child. This null hypothesis was rejected, as a significant correlation between the total scores on the FHI and the total scores on the KMSS were significant (r = .539, p = .001). No other variables were significantly correlated in this analysis.

Ho3: There will be no statistically significant difference/relationship when total scores on two instruments, family hardiness (FHI) and family coping (F-COPES), are compared with marital status, income, age, and educational level of respondent, and age and gender of the child. This hypothesis was rejected, as a significant correlation between the total scores on the FHI and the total scores on the F-COPES were significant (r = .577, p = .000). No other variables were significantly correlated in this analysis.

Table 5

Correlations: Measurements with Demographics

Correlations		FHI Total	F-COPES Total	KMSS Total
Married (Y/N)	Pearson Correlation	0.078	0.167	**.403***
	Sig. (2-tailed)	0.641	0.316	0.018
	n =	38	38	34
Respondent's Age	Pearson Correlation	-0.119	-0.024	-0.190
	Sig. (2-tailed)	0.477	0.885	0.283
	n =	38	38	34
Respondent Education Level	Pearson Correlation	0.213	-0.057	-0.084
	Sig. (2-tailed)	0.199	0.736	0.637
	n =	38	38	34
Family Income	Pearson Correlation	0.169	-0.134	0.042
	Sig. (2-tailed)	0.310	0.422	0.812
	n =	38	38	34
Child's Age	Pearson Correlation	0.082	0.138	-0.199
	Sig. (2-tailed)	0.625	0.408	0.259
	n =	38	38	34
FHI Total	Pearson Correlation	1		
	Sig. (2-tailed)			
	n =	38		
F-COPES Total	Pearson Correlation	**.577****	1	
	Sig. (2-tailed)	0.000		
	n =	38	38	
KMSS Total	Pearson Correlation	**.539****	**.437****	1
	Sig. (2-tailed)	0.001	0.010	
	n =	34	34	34

**Correlation is significant at the 0.01 level (2-tailed).

*Correlation is significant at the 0.05 level (2-tailed).

Additional Analyses

Age

A univariate, between group, analysis was run to look for differences between the respondents' age and scores on the three quantitative instruments. No statistically significant differences were identified between these two demographic variables and the KMSS (M = 3.2, SD = 0.728), the FHI (M = 2.68, SD = 0.319), and the F-COPES (M = 1.861, SD = 0.507).

Marital Status

When respondents (n = 34) level of marital status was compared with scores on the three instruments, no significant differences were found between those respondents in a relationship and those not in a relationship. However, when sample size was accounted for (e.g., Type II SS), there was a significant effect between the FHI and marital status (p = 0.016) as well as age (p = 0.034). When considering fitness of the model, with p = 0.046, with significance at p = 0.05, of the FHI with respondent age and marital status, the second null hypothesis (H0 2) should be rejected in the simple linear regression model, confirming the previous analysis.

Effect Sizes

While there were a minimal number of significant correlations among all the variables, there did appear to be some trends, which resulted in considering effect sizes. Table 6 shows effect sizes for all variables considered. Again, due to imbalances in certain cells (i.e., relationship to child and reported marital status), not all variables are represented in the table. However, the dummy code for married/not married (coded as 1= married 0 =

not married) is included. Several small effect sizes are represented in the table (i.e., $d < 4$). However, total scores on the FHI and respondent's education level ($d = .436$) and the child's age and the total score on the KMSS ($d = -.407$) are approaching a moderate effect size. There was also a moderate effect size for positive perception and being married ($d = .566$). There were also large effect sizes for the total score on the KMSS and being married ($d = .881$). There were large effect sizes in a negative correlation between the respondent's age and perception ($d = 1.174$) and perception and child's age ($d = -.927$). See Table 6 for more information.

Table 6

Correlation and Effect Sizes

	FHI Total[a]			FCOPES Total[a]			KMSS Total[b]			Perception[c]		
	r	*p*	*d*	*r*	*p*	*d*	*r*	*p*	*d*	*r*	*p*	*d*
Married (y/n)	.078	.641	.157	.167	.316	.339	.403	.018	.881	.272	.447	.566
Respondent's Age	-.119	.477	-.240	-.024	.885	-.048	-.190	.283	-.386	-.506	.135	-1.174
Education Level	.213	.199	.436	-.057	.736	-.113	-.084	.637	-.169	-.027	.940	-.055
Income	.169	.310	.343	-.134	.422	-.271	.042	.812	.085	-.067	.854	-.134
Child's Age	.082	.625	.164	.138	.408	.279	-.199	.259	-.407	-.420	.226	-.927

[a] n = 38; [b] n = 34; [c] n = 10

Trends in Responses

Several trends were apparent within the data. In Table 6, a trend of a negative correlation between respondent's age and total scores on the KMSS, FHI, and F-COPES, as well as perception is obvious. Similarly, education level was showed a trend of negative correlation with perception (coded as 0 = negative and 1 = positive) and total scores on the KMSS and F-COPES, but not on the FHI. F-COPES and perception had trends showing negative correlations with respondent's age, education, and income. The KMSS trended toward negative correlations with respondent and child's age and respondent's educational level.

Summary

This chapter reports the results for three groups: The overall group (N = 68) which included demographic and qualitative data only; the quantitative group 1 (n = 38); and the qualitative Group 2 (n = 10) which was derived from Group 1. Groups 1 and 2 were used for the primary analyses in this chapter. Group 1 was comprised of women, ages 18-50; the majority were married, had at least a two-year college degree, and were mothers of children ages one through 22.

The overall group of respondents (N = 68) reported a total of 274 diagnoses for the 68 children, over the course of their lifetime, which were grouped according to ICD 10-CM codes. The Mental, Behavioral, and Neurodevelopmental Disorders (F) category was the largest (n = 158), with categories Q (n = 25), G (n = 23), and P (n = 13) being the next largest groups represented by the sample. A total of 46 (67.6%) reported a diagnosis of some form of ASD. The second largest diagnostic group was for ADD or ADHD (n = 24,

9%). Collectively, these two diagnoses represent a quarter (25.7%) of the diagnoses reported.

Correlation tables were run to determine connections between the three variables (KMSS, FHI, and F-COPES), as well as between these variables and demographic variables. There were significant correlations between all quantitative measures (i.e., F-COPES, FHI, and KMSS), resulting in the first three null hypothesis being rejected. A linear regression confirmed when considering fitness of the model, with $p = 0.046$, with significance at $p = 0.05$, of the FHI with respondent age and marital status. However, this was the only demographic variable correlated with the quantitative assessments. Cohen's D was also run for effect sizes, where several interactions were found to have moderate to large effects ($d > 3$).

CHAPTER V

DISCUSSION

This researcher conducted a mixed methods online study that focused on marital satisfaction, family coping, and family hardiness as reported by 38 parents raising a child with SD while also exploring the responses of ten mothers to the qualitative questions posited in Patrick-Ott's (2011) research study. To expand Patrick-Ott's research to include a quantitative perspective, this researcher used the KMSS (Schumm et al., 2008), the FHI (McCubbin, et al., 1987b), and the F-COPES (McCubbin et al., 1987a). In addition, this researcher based her study on three theories: Systems theory (von Bertalanffy, 1968; Watzlawick et al., 1974), ecological theory (Bronfenbrenner, 1977), and the family stress model (McCubbin & McCubbin, 1987; Patterson & McCubbin, 1983) along with the concepts of chronic sorrow (Olshansky, 1962) and ambiguous loss (Boss, 2006).

Quantitative Review

Marital Satisfaction

Marital satisfaction was defined within the KMSS in three ways: satisfaction with the marriage, the spouse, and the marital relationship (Schumm et al., 1983). The findings from this current study support previous findings that as family coping and as family hardiness increases, marital satisfaction will more than likely increase as well (Neely-Barnes & Dia, 2008; Robinson & Neece, 2015). In the context of this present study, this finding is reassuring as the caregivers were married women raising children with

significant disabilities while also caring for other children and their spouse. One respondent (34) provided a qualitative response that is useful:

> My kid's father and I are divorced. I can't blame it entirely on the disability, but it added to the stress. My current husband made the decision to support a disabled kid. We are much closer and are a team.

Lawrence et al. (2010) discussed increased work around the home, and marital satisfaction, which were negatively correlated. Multiple other researchers have also looked at how an increase in stressors impacts the level of marital satisfaction (Darling et al., 2012; Patrick-Ott & Ladd, 2010; Skolnick, 2007) as well as how finances impact this dynamic (Neely-Barnes & Dia, 2008). Specifically, parents who had positive perceptions of the child's diagnosis were less likely to report marital stress, and less likely to report maternal depression (Neely-Barnes & Dia, 2008).

Family Coping

Coping, as it is defined in the F-COPES, is as follows: 1) the ways a family internally handles difficulties and problems between its members; and, 2) the ways in which the family externally handles problems or demands that emerge outsides its boundaries (McCubbin et al., 1987a, p. 195; McCubbin et al., 2001a). In the current study, this researcher found that when positive family functioning increases in a family, so does family hardiness. This outcome was not supported by Twoy et al. (2007) and Solomon and Chung (2012) who both researched families whose children had been diagnosed with ASD. Twoy et al. and Solomon and Chung found that families with children with ASD often

showed lower levels of functioning when compared with parents of typically developing children as well as parents of children with diagnoses other than ASD.

In this current study, nearly two thirds of the participants also reported an ASD diagnosis for their child at some point in their lifetimes. Yet, the mothers who participated in this study reported a significant ability to cope with the challenges within their home and stressors from without as well.

In this current study, the significant finding that most of these families are handling the challenge of raising a child with significant disability in a positive way and building family resiliency is valuable information that can be used to help other families. A qualitative response from a married mother of a four-year-old child diagnosed with nonverbal autism supports the conclusion that raising a child with a significant disability is challenging and there are numerous problems to work through, but it is not impossible:

> It has given me the ability to look beyond the labels and see the whole person. It has shown me that I have more patience that I thought I could ever possess. I feel having our son has made me stronger in ways I had never thought I could be. Yes, there are moments when it feels like the world's crumbling around my feet and I feel helpless, or the anger of the situation peeks out, but I also have found ways to control and manage my emotions for the good of myself and my family. It has made me a strong person with a determination I never knew I had. (Married mother of a 4-year-old diagnosed with nonverbal autism).

The respondents for this current study are similar, in demographics, to those who participated in Twoy et al.'s (2007) study. All participants in that study were also all married, with the majority aged 31-50, who were also educated with higher than normal incomes (Twoy et al., 2007). Twoy et al. also addressed how ASD, specifically, may be a more significant stressor for mothers than some other diagnoses, reporting "mothers of children with autism experienced more distress than mothers of children with intellectual disabilities without autism" (Twoy et al., 2007, p. 253).

As reported by McCubbin et al. (1983, 1987, 1987a, 1987b), families use a variety of ways to cope with stressors. However, their adjustments, coping, and meaning made affect the outcome for the family, whether the impact of the stressor becomes a crisis (McCubbin & McCubbin, 1987; Patterson & McCubbin, 1983). Furthermore, McCubbin and McCubbin (1987) addressed how time affects the functioning of the family:

> After they have made these initial [adjustments], the family members are called upon to make subsequent changes in an effort to consolidate bringing the entire family into a coherent unit working together around and in support of the newly instituted changes. These processes of restructuring and consolidation evolve over time as families work toward adaptation (p. 23).

Family Hardiness

Family hardiness was defined as the internal strengths and durability of the family unit and is characterized by a sense of control over the outcomes of life events and hardships and includes a view of change as beneficial and growth producing, and an active rather than passive orientation in adjusting to and managing stressful situations (McCubbin

et al., 1987b, p. 125; McCubbin et al., 2001b). As shared above, the findings of this study are clear: There is a positive and significant relationship between coping, resilience, and marital satisfaction as reported by the mothers in this study. As coping strategies are successfully employed, as the family increases its resilience in managing life challenges, and as partners join in a mutually satisfying relationship, the family caregiver reports the successful negotiation of raising a child with significant disabilities. The strengths of the mothers in this study were shared through two narratives as follows:

> I am more patient. I make time for everyone as much as I can. We all help one another. It makes all the difference in the world. (Married mother of a 14-year-old male diagnosed with autism)
>
> It made me more sensitive to his needs and I believe I am more receptive to him…Definitely more open to him and more accepting! (Married mother of a nine-year-old male)

Resources: Education and Income

The women, who comprised the majority of the respondents in this study, reported higher than average education and income levels (USCB, 2012) which appears to have influenced how they responded to their life challenges and enabled them to more successfully managed raising a child with significant disabilities. The findings in this study support the role of both education and income in helping caregivers successfully negotiate their life events. In other studies, an increase of resources (e.g., time, money, knowledge, services) has been correlated to resiliency in families with a child with SD (DHHS, 2013; Gordon, 2009; Knestrict & Kuchey, 2009; Lin, 2000; Melnyk et al., 2001; Solomon &

Chung, 2012). This is not surprising, as an availability of resources (e.g., money, support, etc.) has been previously found to be correlated with reduction of stressors for families, and a significant negative correlation was expected in this study (Baker-Ericzen et al., 2005; Neely-Barnes & Dia, 2008; Robinson & Neece, 2015; Solomon & Chung, 2012).

Meaning-Making by Caregivers

Perception of the Child's Disability and Family Dynamics

According to McCubbin et al. (1987a), the meaning a family attaches to a stressful situation, or the family's appraisal of the situation, my also serve as a part of the family's coping behavior. Incidents that eventually lead to breakdown and dysfunction may depend upon the "presence or absence of explanations which help the family to make sense of that happened, why it happened, and how one's social environment can be arranged to overcome the undesirable situation" (p. 195).

According to McCubbin et al. (1983, 1987, 1987a, 1987b), the resources the family has available to them impact the meaning made of their situation, which is also where bioecological theory (Bronfenbrenner, 1977), and its concepts of nested systems interacts with these variables. People external to the nuclear family act as resources or stressors to the family (McCubbin & McCubbin, 1987; McCubbin et al., 1987a; McCubbin et al., 1987b; Patterson & McCubbin, 1983). However, also in a systemic fashion, the meaning that these external people make of a given situation will impact the meaning that person makes of the situation, which will then impact their interactions with the family of the child with SD, which perhaps impact whether these external people become resources or stressors (Cox & Paley, 1997; Hanson, 1995; von Bertalanffy, 1968; Watzlawick et al.,

1974). For example, again think of a parent with a child with behavioral outbursts (e.g., autism). This parent may not be able to take their child out in public, such as a restaurant or even a store, due to concerns about the child acting out (e.g., stimming, screaming, etc), and society's reaction to these behaviors. When there are siblings, the siblings may also feel that the family is limited on their freedom, due to one child's disability. Recall the mother mentioned about (#17) who mentioned that her family is not able to take vacations, due to her son's behaviors. Collectively, the external environment of the nuclear family has a huge impact on the meaning made by the family caring for the child with SD.

Additionally, other external factors may also impact the parents' perceptions of their child's diagnosis. The same mother who was not able to take vacations (#17) also stated "Our extended family has made sanity possible. I do not know what would have happened without my in-laws, parents, sister, cousins, and one close family friend." Of course, in this instance, the family acted as a resource for this family. However, not all families are supportive; another mother (#19, of a six-year-old female diagnosed with ADHD and various developmental delays) stated "We have lost many friends and family as they are uncomfortable with our children." Another mother of a child with autism (#42), stated: "My family isn't very close to me. They do not understand what I go through. My mom and dad [don't] see my son much because they can't control him. My ex-husband barely gets him as well."

All of these pieces, the external people, their perceptions, as well as other possible supports within the community (e.g., schools, training programs, therapy) combine and impact the way the family functions, or doesn't function (McCubbin & McCubbin, 1987;

McCubbin et al., 1987a; McCubbin et al., 1987b; Patterson & McCubbin, 1983). Within the family, these external variables act as either stressors or resources, but also impact the meaning made by the caregivers, which returns this concept back to the ABC-X model of family stress, and specifically the meaning made by the caregivers (McCubbin & McCubbin, 1987; McCubbin et al., 1987a; McCubbin et al., 1987b; Patterson & McCubbin, 1983).

The meaning made by the caregiver has been the focus of few previous articles (Neely-Barnes & Dia, 2008; Robinson & Neece, 2015). A positive meaning has been associated with better outcomes in regards to family functioning, as well as marital satisfaction, yet a negative perception yields the opposite result (Neely-Barnes & Dia, 2008; Robinson & Neece, 2015; Solomon & Chung, 2012; Twoy et al., 2007). Neely-Barnes and Dia (2008) identified that parents who had positive perceptions of the child's disability were less likely to report marital or familial stress (Neely-Barnes & Dia, 2008). In this study, though, the connections to marital satisfaction (on the KMSS) and family hardiness (on the FHI) were not seen. However, these findings are different than those by Canary (2008), who identified a negative correlation between the diagnosis, levels of perceived support available, and marital satisfaction. Of course, the difference between Neely-Barnes and Dia's study, which looked at variables within the family system, and Canary's study, which looked at variables inside and outside (e.g., perceived support), the family may be why these results seem to be contradictory.

While the quantitative findings in this study yielded three significant relationships between marital satisfaction, coping, and resilience, the qualitative narratives explore the

negative perspective that was held by many of the participants when they answered the questions about raising a child with SD over time. The variable Perception which was yielded in the qualitative coding further demonstrates that the majority of parents saw their experience through a negative perspective even if overall they could share the positive aspects of their lives. One married mother of an 18-year-old male shared her experience:

> It has made me bitter towards people in my life. I feel [others] don't care to know him. It could be cultural reasons behind it. I believe [my] culture do[es] not understand disabilities unless they can physically see them or mental retardation is evident. Otherwise, they view it as poor parenting. It affected my [relationship with] my two older [children] because they were neglected a lot in order to address my son's behavior issues or all his appointments. It has affected my marriage. I have so much resentment towards my husband. I feel he ignores the issues with my son and waits for me to deal with them. It [has] definitely made me a more compassionate person. Taught me to be more empathetic. Number 1: I'm extremely more patient!

Perceptions can be Contradictory

While the quantitative results, such as the quote above, of this study support the finding that positive coping and marital satisfaction are significantly related to family resiliency, the qualitative findings offer a richer insight into the contradictory reports that parents share about the long term experience of raising a child with disabilities. Like other researchers, this author found that the stories of families can be contradictory when parents

report that having a child with a significant disability both solidifies the family system, as well as tearing it apart (Gordon, 2009; Neely-Barnes & Dia, 2008; Robinson & Neece, 2015; Solomon & Chung, 2012; Twoy et al., 2007). However, it is also easy to see the resilience demonstrated within these families. The meaning made (often through reframing) seems to have a significant impact on these families.

The contradictory experience of raising a child with disabilities can be seen in the following narrative from a mother in this study who had thought about aborting her child and daydreams about how her and her family' life would be easier without the stressors of caring for a child with significant disabilities, but chose not to do that, saying that now, "I believe because of my son, I am living!"

Multiple Diagnoses Received by Children

Roughly 274 diagnoses were reported by the 68 caregivers in the larger sample described earlier in this study; this number averages to about four diagnoses per child. It is possible that the actual total number of diagnoses received by these families could be much higher, as other researchers in this field report higher averages in similar families (Lin, 2000; Solomon & Chung, 2012; Twoy et al., 2007). Still, multiple diagnoses which more than likely include inaccurate diagnoses take their toll on a family over time. As found by Shropshire (2017), the knowledge and experience of the medical professional has a profound impact on the accuracy of the diagnosis; this researcher also found that those caregivers who lived near large, teaching medical facilities were more likely to receive an accurate diagnosis for their child than those caregivers who lived a further distance away.

To gain an understanding of what this might feel like for the parent, the reader is encouraged to review Appendix F and imagine being randomly assigned four or five of these diagnoses to research as though your child's life depended on it. Considering the stress reported by the families in the qualitative data, in relation to the experience of receiving a diagnosis, it is easy to imagine how multiple diagnoses can be conceptualized as stressor pile up in the (double) ABC-X model (Hill, 1949; Patterson & McCubbin, 1983).

Application to Theory

The research project was grounded in multiple theories, including systems (von Bertalanffy, 1968; Watzlawick et al., 1974), ecological (Bronfenbrenner, 1977), and the family stress theory (McCubbin & McCubbin, 1987; McCubbin et al., 1987a; McCubbin et al., 1987b; Patterson & McCubbin, 1983; Patterson, 1988). In addition, the concepts of ambiguous loss (Boss, 2006) and chronic sorrow (Olshansky, 1962) were used to explore the narratives.

Systems Theory

Systems theory postulates that everyone in a family is interconnected and anything that effects one member of a family effects everyone else within the system (Cox & Paley, 1997; Hanson, 1995; von Bertalanffy, 1968; Watzlawick et al., 1974). When it comes to families caring for children with significant disabilities, this can be seen in multiple contexts. In most families, only one member of the system has a disability, however this affects all members of the family due to the strain on resources (e.g., time, finances, energy). Children with significant disabilities often require more care, and for longer

periods of time, than their typically developing peers (Baker-Ericzen et al., 2005; Neely-Barnes & Dia, 2008; Robinson & Neece, 2015; Solomon & Chung, 2012). Extended caretaking responsibilities themselves, though, have a reciprocal impact as well.

As extended caretaking requires more time, energy, and finances, there can be fewer of these resources left for other members of the family. The parental relationships with other children and with each other are likely to be strained or even suffer, as the child with the significant disability requires more time and energy from the caretaker, there is less time or energy left for the spouse or other children (Baker-Ericzen et al., 2005; Cox & Paley, 1997; Neely-Barnes & Dia, 2008; Robinson & Neece, 2015; Solomon & Chung, 2012; Twoy et al., 2007). Additionally, depending on the child's abilities, the family as a unit may also be restricted on when, how often, or where they are able to go with the child with SD, as was reported by multiple caregivers in this study. Clearly, even though only one member of the family is assigned a diagnosis, this diagnosis affects all members in the family, in align with the systemic model (Cox & Paley, 1997; Hanson, 1995; von Bertalanffy, 1968; Watzlawick et al., 1974).

Bioecological Theory

In bioecological theory, Bronfenbrenner (1977) suggested that individuals respond to and are impacted by relationships across several nested systems, ranging from other members within the family to systems that no one in the family is directly involved with, but still effects the family (e.g., governmental agencies). These nested systems include things from public policy and what treatments are covered for what illnesses, to cultural or

societal perceptions and how these impact how people with disabilities are perceived. The following narrative illustrates how one caregiver experienced her network of support:

> Raising this child has shown us who our true friends are. Unfortunately, we lost many friends who either could not handle the behaviors or who could not understand the inflexibility of our lives at times. Our extended family has made sanity possible. I do not know what would have happened without my in-laws, parents, sister, cousins, and one close family friend. I have learned to be an advocate for my child, with full understanding of her legal rights. (Respondent 17)

Not only does this mother mention the impact (positive and negative) her child's significant disability had on the family's microsystem, but it also affects how the mother interacts with her exosystem, as impacted by the macrosystem. Another caregiver (#5) also shared about how her child's diagnosis impacts how her family engages with their various systems:

> It has brought awareness to all my family & some can't understand what autism is and tend to shy away from us, but others are closer than ever & rally behind anything we do. we respect & advocate any organization that supports autism.

Family Stress Theory

The family stress theory, originally identified as the ABC-X model by Hill (1949), the model was later expanded to a double ABC-X model, to allow for stress pile-up (Patterson & McCubbin, 1983). In the ABC-X model, the A represents the stressor, B is the

resources, C is the perception, and X represents the outcome of either stress or crisis, as mediated by the AB and C of the family (Hill, 1949). Later, the concept of stress pile up (e.g., being given a diagnosis for one's child, where after the family adjusts their lifestyle, and then a year later are given a different diagnosis, thus invalidating the lifestyle changes made the year previous, and now they must start over at square one with treatment) was added, as well as the possibility that some variables (e.g., extended family) may function as both a stressor (e.g., telling parents how to care for their children) as well as a resources (e.g., childcare) and this new model was named the double ABC-X model (McCubbin & Patterson, 1983). Other researchers have continued to expand on the family stress model, including aspects such as the family life cycle (McCubbin & McCubbin, 1987), and adaptation to stressors (Patterson, 1988).

The stressors of the family are numerous and are impacted by the family life cycle, the child's diagnosis and needs, as well as all other typical stressors for families caring for children (Hall, 1949; Cox & Paley, 1997; McCubbin & McCubbin, 1987; McCubbin et al., 1987a; McCubbin et al., 1987b; Neely-Barnes & Dia, 2008; Robinson & Neece, 2015; Solomon & Chung, 2012). Resources for families of children with significant disabilities are similar to those of parents of typically developing children, but often require additional resources (Baker-Ericzen et al., 2005; Neely-Barnes & Dia, 2008; Robinson & Neece, 2015; Solomon & Chung, 2012).

As found in this study, resources such as education level and income level help mediate the effect of the stressors experience by parents raising children with significant disabilities, which was similar to the results found by Twoy et al. (2007). The meaning

made by the parents of these children has been less focused on in research, but is indispensable when considering the family stress models, when considered though, it also has been found to be a mediating factor in the outcome of stress or crisis (Baker-Ericzen et al., 2005; Hill, 1949; McCubbin & McCubbin, 1987; McCubbin et al., 1987a; McCubbin et al., 1987b; Neely-Barnes & Dia, 2008; Robinson & Neece, 2015; Solomon & Chung, 2012; Twoy et al., 2007). In addition to the systemic aspects of these three models, two additional concepts were included in this analysis to attempt to wholly conceptualize the experience of raising a child with significant disabilities.

Chronic Sorrow

Chronic sorrow, coined and researched by Olshansky (1962), is a concept used to explain the continued loss experienced by parents of children with SD (Gordon, 2009; Patrick-Ott & Ladd, 2010). Olshansky (1962) believed that this chronic sorrow was: 1) a natural byproduct of having a child with significant disabilities, 2) to be expected from these families, 3) inevitable, and 4) ongoing for (at least) the entire lifetime of the child (Gordon, 2009; Patrick-Ott & Ladd, 2010).

In this study, the narrative of parents illustrated that parents of children with significant disabilities have ongoing, conflicting feelings about their child's disability. A mother quoted earlier reported chronic sorrow when she described her son's inability to do things that her typically developing daughters do, or want to do (Olshansky, 1962). However, the mother wraps up her entry with an emphasis on how her son has brought meaning and purpose into her life. It is no wonder, then, that the research about these families can also be confusing, and at times contradictory.

It is also important to also differentiate chronic sorrow from grief and bereavement. In the case of children with significant disabilities, the loss is often not obvious as it is emotional (e.g., the loss of the imagined, or hoped for, child) rather than physical (e.g., the death of the child). Another mother who yearned for a typically developing daughter shared the following about the loss of her imagined child:

> I often feel that we were both cheated. I always wanted a little girl to do all of those mother-daughter things like girl days, shopping, cute shoes, matching outfits, etc. She cannot wear all of the cute shoes because she falls. She doesn't always understand what's happening around her, so we don't have all of the cute inside jokes a mother would have with her 6-year-old. Some days I let it get me down and I just cry.

Ambiguous Loss

Boss (2006) pioneered the concept of "ambiguous loss" as a physical loss that remains psychologically present and/or a psychological loss that remains physically present, as in a child who does not develop in a typically expected way. As illustrated in the narratives of the parents in this study, parents must grieve the "loss" of their imagined ideal child (Boss, 2006; Teel, 1991). Of course, there is no physical loss because this mother still has her child, but not the child she had hoped for. Because her loss is not "real" according to social standards (thus, ambiguous), there is no prescribed social norm for grieving this loss, which can also lead to grief which can cause the individual to feel disenfranchised from their community, family, and many other possible support systems.

This frequently leaves parents and family members scrambling to create new meaning for their life and about the life of their child (Gordon, 2009; Patrick-Ott & Ladd, 2010), which brings these concepts back to the ABC-X models of conceptualizing family stress (Hill, 1949; McCubbin et al., 1987a; McCubbin et al., 1987b; Patterson & McCubbin, 1983). The qualitative variable Perception that was identified from the narratives in this study, support the notion that perception affects both resources and stressors as described in the double ABC-X model. Furthermore, the perception of parents, caregivers, and extended family members will also have a reciprocal impact on how the system functions, as does the available resources for the family such as treatments and societal perceptions of non-typically developing children (Bronfenbrenner, 1977; Hill, 1949; McCubbin et al., 1987a; McCubbin et al., 1987b; Patterson & McCubbin, 1983).

Collectively then, it is important that professionals working with families of children with significant disabilities be aware of the concepts of ambiguous loss and chronic sorrow, and an awareness that these are expected reactions to having a child that may not ever meet the milestones of typically developing children, which should be conceptualized as normal, yet chronic, when viewed in context. Furthermore, it is important to recognize how the various systems that a family exists within can function as a stressor (e.g., when not able to go out to eat due to a child's outbursts due to societal expectations), or as a resource (e.g., a community of families of children with similar disabilities wherein families can engage in their community without fear or judgement, such as Special Olympics), even though the diagnosis exists within an individual member of the family. Finally, placing these concepts into the ABC-X model, helps to identify

which areas of the system that a professional may intervene (Hill, 1949; McCubbin & McCubbin, 1987; McCubbin et al., 1987a; McCubbin et al., 1987b; Patterson & McCubbin, 1983).

Family Therapy

Neely-Barnes and Dia (2008), Solomon and Chung (2012), and Ray et al. (2009), all suggested that family therapists are best poised to assist both with navigating multiple systems, but also the meaning making of the diagnosis for families such as those represented in this study. Perception has been shown, repeatedly, to be an important variable when working with these families who may often feel alienated or isolated due to their child's abilities (Neely-Barnes & Dia, 2008; Robinson & Neece, 2015; Solomon & Chung, 2012; Twoy et al., 2007). Helping a family learn to stop and smell the tulips, to appreciate the windmills, and to enjoy Holland's Rembrandts, may be just the intervention they need (Kingsley, 1987).

Limitations

1. The small sample size (n = 38) for the quantitative results limited generalizability.

2. The dropout rate for this study was 53% as only 38 of 68 participants completed all of the instruments. There are two possible reasons for this high dropout rate: Fatigue due to the length of the survey and emotional discomfort due to the sensitive nature of the study.

3. In hindsight, using an online approach to data collection caused the researcher to make the decision to reduce variables so that the time to complete of the survey would not

exceed 45-60 minutes. Demographic information about the respondent's ethnicity, geographic location, child's age at first diagnosis, all diagnoses ever given to the child, the ages of other children in the home (to determine family life cycle phase), and whether or not the parent worked outside the home would have been useful information.

Implications

The findings from this study yielded the following implications:

1. Parents would benefit from working with family educators and family therapists to gain help in navigating the complex medical system required when raising a child with significant disabilities.

2. Family therapists are encouraged to educate themselves on the needs of caregivers who are attempting to make meaning from the changes in their both their marriage and their family as a result of raising a child with significant disability over time.

3. Medical professionals are encouraged to exercise caution when working with parents as multiple diagnoses and lack of information about the development of their child appears to contribute to the challenges and supports a negative perception of the raising a child with disabilities.

4. Future researchers may want to test the findings of this study by recruiting a sample that includes caregivers who report having both less education and a lower income to learn how mental health professionals and medical professionals can provide resources that moderate stress.

Conclusion

Overall, this study looked at marital satisfaction, family hardiness, and family coping in families of children with significant disabilities. The perception of raising a child with a significant disability, as made by the care taker, and its impact upon the family system was also considered. This study showed that when caregivers perceive and report that their family is coping in a positive way and that their marriage or long-term relationship is satisfying, these two factors are significantly and positively correlated with family resilience when raising a child with significant disabilities. These findings echoed those of previous researchers (Lin, 2000; Neely-Barnes & Dia, 2008; Solomon & Chung, 2012; Twoy et al., 2007). Moderate and large effect sizes were also identified on some variables (Gliner et al., 2017).

Raising children with significant disabilities presents stressors to the family system that are not experienced by typically developing families, in addition to the typical stressors, some of which may even be caused by the professionals who are attempting to help the family when giving reassurances or diagnoses which may later turn out to be inaccurate. By viewing these components through the blended lens of the family stress theory (i.e., the ABC-X model) (McCubbin & McCubbin, 1987; McCubbin et al., 1987a; McCubbin et al., 1987b; Patterson & McCubbin, 1983; Patterson, 1988;), systems theory (von Bertalanffy, 1968; Watzlawick et al., 1974), and bioecological theory (Bronfenbrenner, 1977), and then combined with the concepts of chronic sorrow (Olshansky, 1962) and ambiguous loss (Boss, 2006), it is hoped a more holistic way of looking at families who are caring for children with significant disabilities is demonstrated.

It is this researcher's opinion that the combination of systems theory, ecological theory, and family stress theory when combined with the concepts of ambiguous loss and chronic sorrow, best prepares professionals to work with such families. While much of the research available is still contradictory about how families of children with significant disabilities differ from those of typically developing families, there is no doubt these families are different. As different as Italy and Holland (Kingsley, 1987).

REFERENCES

Ahlert, I. A., & Greeff, A. P. (2012). Resilience factors associated with adaption in families with deaf and hard of hearing children. *American Annals of the Deaf, 157*(4), 391-404. doi: 10.1353/aad.2012.1629

American Psychiatric Association (APA). (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: Author.

Archuleta, K. L., Britt, S. L., Tonn, T. J., & Grable, J. E. (2011). Financial satisfaction and financial stressors in marital satisfaction. *Psychological Reports, 108*(2), 563-576. doi: 10.2466/07.21.PR0.108.2.563-576

Baker, B. (2002). Disorganizing educational tropes: Conceptions of dis/ability and curriculum. *Journal of Curriculum Theorizing, 18*(4), 47-80. doi: 507795955/ 1057896X

Baker, B. L., Blacher, J., & Olsson, M. B. (2005). Preschool children with and without developmental delay: Behavior problems, parents' optimism and well-being. *Journal of Intellectual Disability Research, 49*, 575-590. doi: 106387580/ 0964-2633

Baker-Ericzen, M. J., Brookman-Frazee, L., & Stahmer, A. (2005). Stress levels and adaptability in parents of toddlers with and without autism spectrum disorders. *Research & Practice for Persons with Severe Disabilities, 30*, 194-204. doi: 20486725/1540-7969

Bekenkamp, J., Klasina Groothof, H. A., Bloemers, W., & Tomic, W. (2014). The relationship between physical health and meaning in life among parents of special needs children. *Europe's Journal of Psychology, 10*(1), 67-78. doi: 10.5964/ejop.v10i1.674

Benzies, K. B., Trute, B., Worthington, C., Reddon, J., Keown, L., & Moore, M. (2011). Assessing psychological well-being in mothers of children with disability: Evaluation of the Parenting Morale Index and Family Impact of Childhood Disability Scale. *Journal of Pediatric Psychology, 36*(5), 506-516. doi: 10.1093/jpepsy/jsq081

Black, C., & Enos, R. (1981). Using phenomenology in clinical social work: A poetic pilgrimage. *Clinical Social Work Journal*. 9(1), 34-43.

Blucker, R. T., Elliott, T. R., Warren, R. H., & Warren, A. M. (2011). Psychological adjustment of family caregivers of children who have severe neurodisabilities that require chronic respiratory management. *Families, Systems, & Health, 29*(3), 215-231. doi: 10.1037/a0025146

Boss, P. (2006). *Loss, trauma & resilience*. New York: Norton.

Bronfenbrenner, U. (1977). Toward an experimental ecology of human development. *American Psychologist.* 32(7), 513-531. doi:10.1037/0003-066X.32.7.513

Campbell, K., & Wright, D. W. (2010). Marriage today: Exploring the incongruence between Americans' beliefs and practices. *Journal of Comparative Family Studies, 41*(3), 329-345. doi: 52250697/0047-2328

Canary, H. E. (2008). Creating supportive connections: A decade of research on support for families of children with disabilities. *Health Communication, 23*(5), 413-426. doi: 10.1080/10410230802342085

Cox M. J., & Paley, B. (1997). Families as system. *Annual Review of Psychology, 48*(1), 243. Retrieved from http://www.annualreviews.org/doi/10.1146/annurev.psych.48.1.243

Crane, D. R., Middleton, K. C., & Bean, R. A. (2000). Establishing criterion scores for the Kansas Marital Satisfaction Scale and the Revised Dyadic Adjustment Scale. *American Journal of Family Therapy, 28*(1), 53-60. doi: 10.1080/019261800261815

Creswell, J. W., & Plano Clark, V. L. (2007). *Designing and conducting: Mixed methods research*. (p. 89-150). Thousand Oaks: CA: Sage Publications.

Cronbach, L. J., Jr. (1951). Coefficient alpha and the internal structure of tests. *Psychometrika, 16,* 297-334.

Darling, C. A., Senatore, N., & Strachan, J. (2012). Fathers of children with disabilities: Stress and life satisfaction. *Stress & Health: Journal of the International Society for the Investigation of Stress, 28*(4), 269-78. doi 10.1002/smi.1427

Durkheim, E. (1938). *The rules of sociological method*. Chicago, IL: University of Chicago Press.

Duvall, E. M. (1962). *Family development*. Philadelphia: Lippincott

Fincham, F. D. (1998). Child development and marital relations. *Child Development, 69*(2), 543-74. doi: 10.1111/j.1467-8624.1998.tb06207.x

Gelkopf, M., & Roe, D. (2014). Evaluating outcome domains assessing caregivers of individuals with mental illness: A review. *Family Process, 53*(1), 150-174. doi: 10.1111/famp.12056

Giallo, R., & Gavidia-Payne, S. (2006). Child, parent and family factors as predictors of adjustment for siblings of children with a disability. *Journal of Intellectual Disability Research, 50*(12), 937-948. doi: 10.1111/j.1365-2788.2006.00928.x

Gilbert, A., Lankshear, G., & Petersen, A. (2008). Older family-carers' views on the future accommodation needs of relatives who have an intellectual disability. *International Journal of Social Welfare, 17*(1), 54-64. doi:10.1111/j.1468-2397.2007.00485.x

Gliner, J. A., Morgan, G. A., & Leech, N. L. (2017). *Research methods in applied settings: An integrated approach to design and analysis*. New York, NY: Routledge. ISBN-10: 113885297X

Gordon, J. (2009). An evidence-based approach for supporting parents experiencing chronic sorrow. *Pediatric Nursing, 35*(2), 115-119. doi: 38809808

Greeff, A. P., & Nolting, C. (2013). Resilience in families of children with developmental disabilities. *Families, Systems, & Health, 31*(4), 396-405. doi: 10.1037/a0035059

Hall, H. R., Neely-Barnes, S. L., Graff, J. C., Krcek, T. E., Roberts, R. J., & Hankins, J. S. (2012). Parental stress in families of children with a genetic disorder//disability and the Resiliency model of family stress, adjustment, and adaptation . *Issues in Comprehensive Pediatric Nursing, 35*(1), 24-44. doi:10.3109/01460862.2012.646479

Hanson, B. G. (1995). *General systems theory: Beginning with the wholes*. New York: Taylor & Francis. ISBN: 1-56032-345-0

Hill, R. (1949). *Families under stress: Adjustment to the crisis of war, separation, and reunion*. New York: Harper & Row.

Kapp, L., & Brown, O. (2011). Resilience in families adapting to Autism spectrum disorder. *Journal of Psychology in Africa, 21*(3), 459-464. doi: 77530368/1433-0237

Khazan, I., McHale, J. P., & Decourcey, W. (2008). Violated wishes about division of childcare labor predict early coparenting process during stressful and nonstressful family evaluations. *Infant Mental Health Journal, 29*(4), 343-361. doi: 10.1002/imhj.20183.

Kieckhefer, G. M., Trahms, C. M., Churchill, S. S., Kratz, L., Uding, N., & Villareale, N. (2014). A randomized clinical trial of the Building on Family Strengths program: An education program for parents of children with chronic health conditions. *Maternal and Child Health Journal, 18*(3), 563-574. doi: 10.1007/s10995-013-1273-2

Kingsley, E. P. (1987). *Welcome to Holland*. Retrieved from: https://www.facebook.com/notes/stop-discrimination-against-special-needs/welcome-to-holland-by-emily-perl-kingsley-c1987-by-emily-perl-kingsley-all-right/312159348880123

Knestrict, T., & Kuchey, D. (2009). Welcome to Holland: Characteristics of resilient families raising children with severe disabilities. *Journal of Family Studies, 15*(3), 227-244. doi: 49116590.

Lawrence, E., Rothman, A. D., Cobb, R. J., & Bradbury, T. N. (2010). Marital satisfaction across the transition to parenthood: Three eras of research. In M. S. Schulz, M. K. Pruett, P. K. Kerig, & R. D. Parke (Eds.), *Strengthening couple relationships for optimal child development: Lessons from research and intervention* (pp. 110-119). Washington, DC: American Psychological Association.

Lin, S. (2000). Coping and adaptation in families of children with cerebral palsy. *Exceptional Children, 66*(2), 201-218. doi: https://doi.org/10.1177/001440290006600205

Lindo, E. J., Kliemann, K. R., Combes, B. H., & Frank, J. (2016). Managing stress levels of parents of children with developmental disabilities: A meta-analytic review of interventions. *Family Relations, 65*(1), 207-224. doi:10.1111/fare.12185

Malia, J. A. (2007). A reader's guide to family stress literature. *Journal of Loss and Trauma, 12*, 223-243. doi: 10.1080/15434610600854400.

Marshall, D. (Nov. 27, 2017). Personal Communication.

McCubbin, H. I. & McCubbin, M. (Eds.) (1987). Family stress theory and assessment. In H. I. McCubbin & A. I. Thompson (Eds.), *Family assessment inventories: Research and practice* (pp. 3-34). Madison, WI: University of Wisconsin System.

McCubbin, H. I., & McCubbin, M. A. (1988). Typologies of resilient families: Emerging roles of social class and ethnicity. *Family Relations, 37*, 247–254. doi: 10.2307/584557

McCubbin, H. I., McCubbin, M. A., & Larsen, A. S. (2001a). Family Crisis Oriented Personal Evaluation Scales (F-COPES). In J. Touliatos, B. F. Perlmutter, & M.A. Straus. *Handbook of family measurement techniques: Abstract*. Volume 1. (p. 276-277). Thousand Oaks, CA: Sage.

McCubbin, H. I., McCubbin, M. A., & Thompson, A. I. (2001b). Family Hardiness Index (FHI). In J. Touliatos, B. F. Perlmutter, & M.A. Straus. *Handbook of family measurement techniques: Abstract*. Volume 1. (p. 266-267). Thousand Oaks, CA: Sage.

McCubbin, H. I., McCubbin, M. A., & Thompson, A. I. (Eds.) (1987b). FHI: Family Hardiness Index. In H. I. McCubbin & A. I. Thompson (Eds.), *Family assessment inventories: Research and practice* (pp. 125-132). Madison, WI: University of Wisconsin System.

McCubbin, H. I., McCubbin, M. A., & Thompson, A. I. (1997). Families under stress: what makes them resilient? *Journal of Family & Consumer Sciences, 89*(3), 2-11. doi: 507598556/1082-1651

McCubbin, H. I., Olson, D. H., & Larsen, A. S. (1987a). F-COPES: Family Crisis Oriented Personal Evaluation Scales. In H. I. McCubbin & A. I. Thompson (Eds.), *Family assessment inventories: Research and practice* (pp. 195-210). Madison, WI: University of Wisconsin System.

Melnyk, B. M., Feinstein, N. F., Moldenhouer, Z., & Small, L. (2001). Coping in parents of children who are chronically ill: Strategies for assessment and intervention. *Pediatric Nursing, 27*(6), 548-558. doi: 106904476/0097-9805

Morse, R. S., Rojahn, J., & Smith, A. M. (2014). Effects of behavior problems, family functioning, and family coping on parent stress in families with a child with Smith-Magenis Syndrome. *Journal of Developmental and Physical Disabilities, 26*(4), 391-401. doi: 10.1007/s10882-014-9367-3

Nabors, L. A., Kichler, J. C., Brassell, A., Thakkar, S., Bartz, J., Pangallo, J., Van Wassenhove. B., & Lundy, H. (2013). Factors related to caregiver state anxiety and coping with a child's chronic illness. *Families, Systems, & Health, 31*(2), 171-180. doi: 10.1037/a0031240

Neely-Barnes, S. L., & Dia, D. A. (2008). Families of children with disabilities: A review of literature and recommendations for interventions. *Journal of Early and Intensive Behavior Intervention, 5*(3), 93-107. doi: : 10.1037/h0100425

Neighbour, R. H., (1985). The family life-cycle. *Journal of the Royal Society of Medicine, 78*(8), 11-15.

Olshansky, S. (1962). Chronic sorrow: A response to having a mentally defective child. *Social Casework, 43,* 190-193.

Olshansky, S. (1966). Parent responses to a mentally defective child. *Mental Retardation, 4*(4), 21-23.

Olshansky, S., Johnson, G. C., & Sternfeld L. (1963). Attitudes of some GPs towards institutionalizing mentally retarded children. *Mental Retardation, 1*(1), 18-23.

Opini, B. (2016). Walking the walk: Towards a more inclusive field of disability studies. *International Journal of Inclusive Education, 20*(1), 67-90. doi: 10.1080/13603116.2015.1073800

Ouellette-Kuntz, H., Blinkhorn, A., Rouette, J., Blinkhorn, M., Lunsky, Y., & Weiss, J. (2014). Family resilience -- An important indicator when planning services for adults with intellectual and developmental disabilities. *Journal on Developmental Disabilities, 20*(2), 55-66.

Patrick-Ott, A. S. (2011). *The experience of chronic sorrow in parents who have a child diagnosed with a significant disability: Investigating chronic sorrow across parental life.* (Doctoral Dissertation) Texas Woman's University, ProQuest. UMI Dissertations Publishing. 3497855.

Patrick-Ott, A. S., & Ladd, L. (2010). The blending of Boss's concept of ambiguous loss and Olshansky's concept of chronic sorrow: A case study of a family with a child who has significant disabilities. *Journal of Creativity in Mental Health, 5*(1), 73-86. doi: 10.1080/15401381003627327.

Patterson, J. M. (1988). Families experiencing stress: The Family Adjustment and Adaptation Response Model: Applying the FAAR Model to health-related issues for intervention and research. *Family Systems Medicine, 6*(2), 202-237. doi: 0736-1718/SN050847.

Patterson, J. M., & McCubbin, H. I. (1983). The impact of family life events and changes on health of a chronically ill child. *Family Relations, 32*(2), 255.

Ray, J. A., Pewitt-Kinder, J., & George, S. (2009). Partnering with families of children with special needs. *Young Children, 64* (5), 16-23. doi: EJ868190/1538-6619

Robinson, M., & Neece, C. L. (2015). Marital satisfaction, parental stress, and child behavior problems among parents of young children with developmental delays. *Journal of Mental Health Research in Intellectual Disabilities, 8*(1), 23-46. doi: EJ1049758/1931-5864

Roos, S. (2013). *Chronic sorrow: A living loss.* London: Routledge Taylor & Francis Group.

Roper, S. O., Allred, D. W., Mandleco, B., Freeborn, D., & Dyches, T. (2014). Caregiver burden and sibling relationships in families raising children with disabilities and typically developing children. *Families, Systems & Health: The Journal of Collaborative Family Healthcare, 32*(2), 241-246. doi: 10.1037/fsh0000047

Schumm, W. R., Crock, R. J., Likcani, A., Akagi, C. G., & Bosch, K. R. (2008). Reliability and validity of the Kansas Marital Satisfaction Scale with different response formats in a recent sample of U.S. Army personnel. *Individual Differences Research, 6*(1), 26-37. doi: 31690398/1541-745X

Schumm, W. R., Nichols, C. W., Schectman, K. L, & Grigsby, C. C. (1983). Characteristics of responses to the Kansas Marital Satisfaction Scale by a sample of 84 married mothers. *Psychological Reports, 53,* 567-572. doi: 507514487/00332941

Schumm, W. R., Paff-Bergen, L. A., Hatch, R. C., Obiorah, F. C., Copeland, J. M., Meens, L. D., & Bugaighis, M. A. (1986). Concurrent and discriminant validity of the

Kansas Marital Satisfaction Scale. *Journal of Marriage and the Family, 48*(2), 381-387. doi: 10.2307/352405

Shek, D. L., & Tsang, S. M. (1993). The Chinese version of the Kansas Marital Satisfaction Scale: Some psychometric and normative data. *Social Behavior & Personality: An International Journal, 21*(3), 205-214. doi: 12964706/ 03012212

Shropshire, S. (2017). Klippel-Feil syndrome: A study of parent and caregivers' experience of diagnosis, health service uses, and online support in a rare disease population. (Unpublished master's thesis.) Texas Woman's University: Denton, Texas.

Skolnick, A. (2007). Grounds for marriage: How relationships succeed or fail. In. A. S. Skolnick, & J. H. Skolnick (Eds.). *Family in Transition*. (p. 192-202) Boston, MA: Pearson.

Solomon, A. J., & Chung, B. (2012). Understanding Autism: How family therapists can support parents of children with autism spectrum disorders. *Family Process, 51* (2). 250-264. doi: 10.1111/j.1545-5300.2012.01399.x.

Stadler, H. A., Willing, K. L., & Eberhage, M. G. (1988). Impairment: Implications for the counseling profession. *Journal of Counseling & Development, 66,* 258-260. doi: 4962753/0748-9633

Taanila, A., Syrjälä, L., Kokkonen, J., & Järvelin, M. (2002). Coping of parents with physically and/or intellectually disabled children. *Child: Care, Health & Development, 28*(1), 73-86. doi: 10.1046/j.1365-2214.2002.00244.x

Teel, C. S. (1991). Chronic sorrow: Analysis of the concept. *Journal of Advanced Nursing, 16*(11), 1311-1319. doi: 10.1111/j.1365-2648.1991.tb01559.x

Turnbull, A. P., & Turnbull, H. R. (1997). *Families, professionals, and exceptionality: A special partnership.* Columbus, OH: Prentice Hall.

Twoy, R., Connolly, P. M., & Novak, J. M. (2007). Coping strategies used by parents of children with autism. *Journal of the American Academy of Nurse Practitioners, 19*(5), 251-260. doi: 10.1111/j.1745-7599.2007.00222.x

U.S. Census Bureau (USCB); American Community Survey, 2015 American Community Survey 1-Year Estimates. (2016a). *Disability characteristics. Table S1810.* Retrieved from: https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS_15_1YR_S1810&prodType=table

U.S. Census Bureau (USCB); American Community Survey, 2015 American Community Survey 1-Year Estimates. (2016b). *Selected economic characteristics for the civilian noninstitutionalized population by disability status. Table S1811.* Retrieved from: https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS_15_1YR_S1811&prodType=table

U.S. Census Bureau (USCB). *News Brief: Nearly 1 in 5 people have a disability in the U.S.,* Census Bureau Reports. (2012). Retrieved from: https://www.census.gov/newsroom/releases/archives/miscellaneous/cb12-134.html

U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. (2013). *The National Survey of*

Children with Special Health Care Needs Chartbook 2009–2010. Rockville, Maryland: U.S. Department of Health and Human Services.

U.S. Centers for Medicare & Medicaid Services (CMS). (2017, Aug. 31). ICD-10. Retrieved from: https://www.cms.gov/Medicare/Coding/ICD10/index.html

von Bertalanffy, L. (1968). *General system theory: Foundations, development, applications.* NewYork: George Braziller.

Walsh, F. (2003). Family resilience: A framework for clinical practice. *Family Process 42*(1), 1-18. doi: 10.1111/j.1545-5300.2003.00001.x

Watzlawick, P., Weakland, J., & Fisch, R. (1974, 2011). *Change: Principles of problem formulation and problem resolution*. New York: W. W. Norton & Co.

APPENDIX A

Informed Consent

Informed Consent

The experience of raising a child with significant disabilities is unique for every parent and family. This survey expands the principal author's previous research which focused on a small group of parents raising children with significant disabilities who lived at home at least 11 months a year. The information these parents shared about how they learned to cope and manage their family while raising their child with significant disabilities forms the basis for the qualitative questions in this survey. To continue to build the body of knowledge about families with children having significant disabilities, we are also asking participants in this study to complete three quantitative instruments that focus on family hardiness, family coping, and marital satisfaction. However, you do not have to be in a significant adult relationship to participate in this study. We hope that you will find the time to complete this survey and let us know if you would like to receive a summary of our findings at the conclusion of the study.

For the purposes of this study, "Significant Disability" is defined as: Significant disabilities are also known as multiple disabilities and severe multiple disabilities. The Individuals with Disabilities Education Act describes this disability as those that mean concomitant impairments (such as mental retardation, blindness, mental retardation and orthopedic impairment, like cerebral palsy etc). The combination causes severe problems so that the individual cannot be accommodated in special programs solely for one of the impairments" (34 C.F.R. §30[b] [6]). The caregiving duties that extend past the infancy stage into the adult years (continued spoon feeding, incontinence, continued supervision, poorly developed self-help skills, etc.), are all associated with raising a child with significant disabilities.

The purpose of this online study is to provide parents and caretakers of children with significant disabilities with the opportunity to describe their experience of raising a child with disabilities. This study is open to any person that is providing care for a child with significant disabilities including parents, adult siblings, grandparents or extended family members, legal guardian, and caretakers.

The three questions below identify the criteria to participate in this study. If you can answer "yes" to each of these questions, then we invite you to continue through the study.

1. I am the primary caretaker (parent, step-parent, grandparent, guardian, adult sibling, extended family member or guardian) of a child diagnosed with significant disabilities that lives in my home at least 11 months of the year.
2. I am an adult that is at least 18 years old.
3. I can read English at the 3rd grade level.

Thank you for your participation in this study as we believe that learning more about how parents raise a child with significant disabilities will be useful for other parents and professionals working in this field.

The researchers will try to prevent any problem that could happen because of this research. You should let the researchers know at once if there is a problem and they will help you. However, TWU does not provide medical services or financial assistance for injuries that might happen because you are taking part in this research. You can contact any of the three researchers at their email addresses located at the top of this survey.

This survey will take approximately 35-45 minutes. Thank you for your participation in this study as we believe that learning more about raising a child with significant disabilities will be useful for other parents and professionals working in this field. At the end of the survey, you will have the choice to send this survey to another person. You will also have the opportunity to decide if you would like to be contacted in the future by these researchers (to obtain an executive summary of the results for this project or participate in follow up projects with these researchers).

Please be aware: If you decide to request an executive summary or volunteer to participate in future research, please be aware that your information will be kept confidential, but is no longer anonymous.

This survey includes 12 demographic questions about your family, eight qualitative (open-ended) questions about your experience caring for a child with significant disabilities, and concludes with three different quantitative (multiple choice) measurements.

If you leave this survey, you will be unable to save your work and return at a later time. Your agreement to participate in this study will be assumed if you click the ‘Continue’ button below. Once you have clicked to continue the survey, you have given your consent to participate in this survey.

Risk: Participating in research takes time and can cause fatigue or emotional discomfort. If you become fatigued or experience any type of discomfort, you may exit the survey at any time. You are under no obligation to continue this survey. You will be unable to save your progress to return at a later time.

Risk: Participating in research can cause psychological harm. If you experience any psychological discomfort, please access the resource list at the end of this survey entitled Community Resources.

Risk: Loss of confidentiality. While you will not be asked for your name, there is a potential risk of loss of confidentiality in email, downloading, and internet transactions. Confidentiality will be protected to the extent that is allowed by law. The information you

share is confidential as your email address is kept separately from this data. If you choose to receive a copy of our final results, you may share that contact information on a Get Results link that is separate from this survey and your information. If you chose to participate in future research, your anonymity may also be lost.

Risk: Loss of time. This survey will take approximately 35-45 minutes to complete.

This research study has been approved by the TWU Institutional Review Board. This means that the study meets all standards of ethical requirements; assures protection of participant's rights, and participants have the right to withdrawal at any time.

The researchers will try to prevent any problem that could happen because of this research. You should let the researchers know at once if there is a problem and they will help you. However, TWU does not provide medical services or financial assistance for injuries that might happen because you are taking part in this research.

APPENDIX B

Survey

Survey

1) Please click on the response below that best describes your relationship with the child with significant disabilities.

Mother/Stepmother/Foster mother.
Father/Stepfather/Foster father
Adult Sibling
Grandparent
Extended Family Member
Guardian
Caretaker
Other

2) What was your age at your last birthday?

18-20
21-30
31-40
41-50
51-60
61-70
70+

3) What is your current marital status?

Single/Never Married
Married/Cohabitating/Civil Union/Committed Relationship
Separated/Divorced
Widowed

4) What was the highest educational level you have completed?

High School or GED
2 Year Degree/Trade School (Associates)
4 Year Degree (Bachelors)
Master's Degree
PhD
Other (please specify) _____

5) What is your gross annual household income?

<$25,000
$26,000-$50,000
$50,001-$75,000
$75,001-$100,000
$100,001-$150,000
$150,001-$200,000
>$200,001

The following questions are about all the children in your family living in your home

Questions 6-9 concern your child with significant disabilities and questions 10 and 11 ask about the other children in the family.

6) Please select all of the answers below that best describe your child's situation

My child lives with me at least 11 months of the year.
My child leaves the house every day to go to school for at least six hours.
My child leaves the house every day to attend day rehabilitation or receive caregiver services for some portion of the day.
My child stays at home for the majority of the day and leaves only for events such as doctor's appointments or visits with family members.

7) What is the gender of your child with significant disabilities?

Male
Female

8) What was the age of this child at his/her last birthday? [Text Box (TB)]

9) Over the course of your child's life you may have received several diagnoses for your child's condition. In the space below, please tell us what those diagnoses were and also please include the most recent diagnosis that you have. [TB]

10) Are there other children living in the same home as the child with significant disabilities?

Yes
No

11) How many other children currently live in the same home with the child with significant disabilities at least 11 months of the year? [TB]

12) Are you aware of anyone else completing this survey regarding the same child with significant disabilities?

Yes
No

The next seven questions ask you to consider specific areas of your experience raising a child with significant disabilities. The final question provides you with an opportunity to share/expand on any other part of your family's story that you feel is important for us to know.

13) When you first realized that your child was not reaching the major developmental milestones for his/her developmental age, what was your reaction? [TB]

14) When you received the initial diagnosis for your child, what was your reaction? What process did you use to help you understand your child's diagnosis and deal with your emotions? [TB]

15) How did receiving a diagnosis for your child impact how you cared for your child on a day to day basis -- and over the years? [TB]

16) Please consider the emotional journey you have taken since the birth of your child and the diagnosis of his/her disorder. Would you say that you have experienced an "ebb and flow" of emotions? Is there a "changelessness" about your parenting of your child? [TB]

17) As a parent of a child with significant disabilities, how have you managed to care for yourself? What has helped you separate your own individuality from that of being your child's parent? [TB]

18) How has the experience of raising a child with significant disabilities changed you? How has it affected your relationship with your other children or your spouse/partner? [TB]

19) How do you see the future for yourself and your child? What plans have you made for your child when you are not able to care for him/her? [TB]

20) How has raising a child with significant disabilities impacted your relationship with friends or extended family members? How has it changed the way you interact with the medical profession and organizations that serve children with significant disabilities? [TB]

21) It is now your turn to share your story of your family in the space below. Feel free to expand on anything you said in the specific questions above or share your thoughts or experiences about something else important in your life or in your family. [TB]

Kansas Marital Satisfaction Survey

The following three questions ask about your current significant adult relationship (official marital ceremony is not a prerequisite).If you are not currently in a committed relationship, please skip to the next section (Family Hardiness Index), number 25.

Please click the circle that describes your opinion of your current partnership (if applicable).

[Likert Scale: Extremely Dissatisfied; Very Dissatisfied; Somewhat Dissatisfied; Mixed; Somewhat Satisfied; Very Satisfied; Extremely Satisfied]

22) How satisfied are you with your marriage (partnership)?
23) How satisfied are you with your husband/wife as a spouse?
24) How satisfied are you with your relationship with your husband/wife?

Family Hardiness Index

In the next two sections below, please read each statement below and decide to what degree each describes your family. Is the statement False (0), Mostly False (1), Mostly True (2),or True (3) about your family? Click on the circle below that matches your feelings about each statement. Please respond to each and every statement.

[Likert Scale: False; Mostly False; Mostly True; True]

In our family….

25) Trouble results from mistakes we make
26) It is not wise to plan ahead and hope because things do not turn out anyway
27) Our work and effort are not appreciated no matter how hard we try and work
28) In the long run, the bad things that happen to us are balanced by the good things that happens to us
29) We have a sense of being strong even when we face big problems
30) Many times I feel I can trust that even in difficult times things will work out
31) While we don't always agree, we can count on each other to stand by us in times of need
32) We do not feel we can survive if another problem hits us
33) We believe that things will work out for the better if we work together as a family
34) Life seems dull and meaningless
35) We strive together and help each other no matter what
36) When our family plans activities we try new and exciting things
37) We listen to each others' problems, hurts and fears
38) We trend to do the same things over and over...it's boring
39) We seem to encourage each other to try new things with others
40) It is better to stay at home than go out and do things with others
41) Being active and learning new things are encouraged
42) We work together to solve problems
43) Most of the unhappy things that are due to bad luck
44) We realize our lives are controlled by accidents and luck

Family-COPES

For the final sections: First, read the list of "Response Choices" one at a time. Second, decide how well each statement describes your attitudes and behaviors in response to problems or difficulties. If the statement describes your response very well, the click the 5th circle (Strongly Agree) indicating that you strongly agree; the if the statement describes your responses to some degree, then select a number 2 (Moderately Disagree), 3 (Neither Agree or Disagree) or 4 (Moderately Agree) to indicate how much you agree or disagree with the statement about your responses.

[Likert Scale: Strongly disagree; Moderately Disagree; Neither Agree or Disagree; Moderately Agree; Strongly Agree]

When we face problems or difficulties in our family we respond by:

45) Sharing our difficulties with relatives
46) Seeking encouragement and support from friends
47) Knowing we have the power to solve major problems
48) Seeking information and advices from persons in other families who have faced the same or similar problems
49) Seeking advice from relatives (grandparents, etc.)
50) Seeking assistance from community agencies and programs designed to help families in our situation
51) Knowing that we have the strength within our won family to solve problems.
52) Receiving gifts and favors from neighbors (e.g., food, taking in the mail, etc.)
53) Seeking information and advisor from the family doctor
54) Asking neighbors for favors and assistance
55) Facing problems "head-on" and trying to get a solution right away
56) Watching television
57) Showing that we are strong
58) Attending church services
59) Accepting stressful events as a fact of life
60) Sharing concerns with close friends
61) Knowing luck plays a big part in how well we are able to solve family problems
62) Exercising with friends to stay fit and reduce tension
63) Accepting that difficulties occur unexpectedly
64) Doing things with relatives (get togethers, dinners, etc.)
65) Seeking professional counseling and help for family difficulties

66) Believing that we can handle our own problems
67) Participating in church activities
68) Defining the family problem in a more positive way so that we do not become too discouraged
69) Asking relatives how they feel about the problems we face
70) Feeling that no matter what we do to prepare, we will have difficulty handling problems
71) Seeking advice from a minister
72) Believing if we wait long enough, the problem will go away
73) Sharing problems with a neighbor
74) Having faith in God

APPENDIX C

Approval to Use KMSS from Walter Schumm

Approval to Use KMSS from Walter Schumm

Schumm, Walter [schumm@k-state.edu]
To: Thornton, Miranda
Date: 4/15/2013

Dear Miranda,

You are welcome to use the KMSS at no cost for your dissertation research or any other academic, non-profit endeavor.

I have attached some older summary material about the KMSS.

Larry Kurdek used the KMSS extensively with same-sex couples, so just check out his research that looked at marital satisfaction. He tended to use a nine point response set rather than the regular five or seven that I tend to use. He had some of the most extensive data on test-retest reliability for the KMSS but he never published most of it. I wanted him to do so but he almost never did and now he has died. I think I recall seeing some other scholars studying same-sex couples having used it as well, but I cannot recall which scholars at the moment.

Thanks,

Walter Schumm

APPENDIX D

Letter to Websites/ Webmasters

Letter to Websites/ Webmasters

Department of Family Sciences
College of Professional Education
P.O. Box 425769, Denton, TX 76204-5769
940-898-2685 Fax: 940-898-2676
famsci@twu.edu www.twu.edu/family-sciences

Counseling & Family Therapy Clinic

Academic Programs

Counseling & Development

Early Childhood Development & Education

Family Studies

Family Therapy

Director or Webmaster:

My name is Dr. Amy Ott and I am associated with the Family Sciences Department at Texas Woman's University (TWU) in Denton, Texas. I am working with Miranda Thornton and Dr. Linda Ladd on this project as we are interested in studying how the experience of raising a child that has been diagnosed with significant disabilities impacts the parents and other adults who are providing care for the child.

The title of this study is: *Chronic Sorrow, Family Hardiness, Family Coping, Marital Satisfaction as Reported by Adults or Parents Raising a Child with Significant Disabilities: An Online Study*.

This letter is a request to post a flyer about this research on your organization's website so that parents who are raising a child with significant disabilities can be recruited to participate as volunteers in this research. The length of time to complete this survey is 35-45 minutes.

This study meets the standards of ethical requirements as established by the Institutional Review Board at TWU. This study assures each participant the right of voluntary participation; any participant may withdraw from this study at any time. The information shared by each participant will remain confidential as the website is designed so that no identifiable information will be attached to the survey when it is submitted, such as email addresses or routing numbers. There is a potential risk of loss of confidentiality in email, downloading, and internet transactions.

Interested persons can contact either researcher below to request a flyer and a flyer will be emailed back. Email addresses of interested persons will not be collected.
All information about the study and how to access the study is included on the study recruitment flyer. Interested persons can learn more about the online study at

www.SpecialFamiliesSpecialStories.com. If they choose to participate, they will not be contacted by anyone involved with this study. Participation is voluntary and anonymous. If the participants wish to receive an executive summary of this study, they may click on a link that will take them to a separate survey where they can request an executive summary of the study by leaving their email address.

However, requesting an executive summary will cause participants to lose their anonymity.

If your organization would be willing to post a recruitment flyer about this study, please email me your requirements and instructions. I appreciate your consideration of this request.

I have attached a copy of the recruitment flyer that informs potential participants and includes a link to the actual survey.

Thank you, again, for your consideration.

Amy Ott
Amy Ott, PhD, LPCS

Cell phone: 940-368-7176
Email address: amysuepatrickott@msn.com

Miranda Thornton
Miranda Thornton, MS, LMFT-Associate
Cell phone: 940-594-4482
Email address: mthornton1@twu.edu

APPENDIX E

Recruitment Flyer

Recruitment Flyer

Department of Family Sciences

College of Professional Education

P.O. Box 425769, Denton, TX 76204-5769

Counseling & Family Therapy Clinic

Academic Programs

Counseling & Development

Early Childhood Development & Education

Family Studies

Family Therapy

ANNOUNCING AN ANONYMOUS ONLINE RESEARCH STUDY

Chronic Sorrow, Family Hardiness, Family Coping, and Marital Satisfaction as Reported by Parents or Adults Raising a Child with Significant Disabilities: An Online Study

Do you have a child that has been diagnosed with significant disabilities?

www.Special-Families-Special-Stories.com

If you answered "Yes", then you are invited to participate in an online research study that will help these researchers understand how raising a child with significant disabilities has impacted you as a parent. The researchers listed above are investigating how parents report their experience of chronic sorrow, family hardiness, family coping, and marital satisfaction as they raise their child with significant disabilities.

A potential benefit to you for your participation in this study is the opportunity to help other parents and professionals understand the experience of raising a child with significant disabilities. Participants will also have the opportunity to request a summary of the research findings and gain an awareness of how parents manage their experiences of stress and balance their marital/couple relationship. However, a request for a summary will cause participants to lose their anonymity in this survey.

You are invited to become a participant in this study if ALL of the following statements are TRUE:

1. You are the primary care provider (parent, step-parent, grandparent, adult sibling, extended family member or guardian) of a child diagnosed with significant disabilities that lives in your home at least 11 months of the year.
2. You are an adult that is at least 18 years old.
3. You can read English at the 3rd grade level.

If all statements are true for you and you would like to participate in this study, you may go to the www.SpecialFamiliesSpecialStories.com to learn more about the study.

Dr. Amy Ott	**Miranda Thornton**	**Dr. Linda Ladd**
amysuepatrickott@msn.com	**mthornton1@mail.twu.edu**	**lladd@twu.edu**

Note: This research is part of an ongoing research study in the Department of Family Sciences at Texas Woman's University (TWU) in Denton, Texas and has been approved by the TWU Institutional Review Board. This approval signifies that this study has met all standards of ethical requirements, assuring rights to voluntary participation and withdrawal at any time. Complete confidentiality will be maintained throughout the entire study. The research website is designed so that no information containing your identity, including email addresses or routing numbers, will be attached to the survey when it is submitted. No participant will be contacted at any time by any person. This survey will take approximately 30-45 minutes to complete. There is a potential risk of loss of confidentiality in email, downloading, and internet transactions.

APPENDIX F

List of Reported Diagnoses

List of Reported Diagnoses

Autism -- PDD-NOS
General Developmental Delay.
Monosomy 1p36
Pre-term birth
Tracheomalacia
Laryngomalacia
Stenosis
BRONCHOPULMONARY DYSPLASIA
Hepatoblastoma
Failure to Thrive
Moderate to Severe Hearing Loss
Portal Hypertension
Oral Aversion
Bi-lateral Vocal Cord Paralysis
ADHD
Sensory Process Disorder
Developmental Delays
Autism
ADHD
Learning Disabilities
PDD NOS
Severe Autism
ADD
ADHD
Bipolar
Mentally Challenged
Mentally Retarded
Schizophrenic
Developmental Delay with Autistic Tendencies,
Autism
Schizoaffective Disorder
Drug Addict
Bipolar
Mental Retardation

Autism
Tourette syndrome
Autism spectrum disorder
Sensory Processing Disorder
Tourette
Asperger's
ADHD
OCD
General Anxiety Disorder
Asperger's
ASD
Mood Disorder NOS
ADHD NOS
General Anxiety Disorder NOS
Down syndrome
Spectrum Disorder
Agenesis Corpus Callosum
Agenesis Septum Pellucidum
Bilateral Open Lip Schizencephaly
Cerebral Palsy
Epilepsy
Septo Optic Displaysia
High Tone
Delayed Gastric Emptying
Reflux
Nystagmus
Severe Encephalopathy
Hip Displaysia
Down Syndrome
MR
PDD-NOS
Autism
Autism
Global Delay
Severe Asthma

Autistic Disorder	**Autism**
ADHD	**Self Injurious Behavior**
Sensory Processing Disorder	**Conduct Disorder**
ASD	**Encephalopathy**
PDD-NOS	**Chronic Constipation**
Receptive Language Disorder	**Encopresis**
Hyperlexia	**Sensory Issues**
Echolasia	**Epilepsy**
ADHD	**Right Hemiparesis**
OCD	**Intellectual Impairment**
Infantile Cerebral Palsy	**Left Hemispherectomy**
Spastic Quadriplegia	**Asthma**
Premature Birth Hypoxia	**Brain injury**
Dilated Ventricles in Both Hemispheres	**Legally Blind**
	Cerebral Palsy
Hydrocephalus Exvacum	**ADD**
Autism	**Autism**
ADHD	**Diabetes**
Autism	**Schizoaffective Disorder**
PDD-NOS	**Severe Mental Retardation**
Autistic- like	**Congenital Heart Defects (tetralogy of fallot)**
Premature	**DiGeorge syndrome**
Respiratory Distress	**Stroke**
Low Birth Weight	**Cerebral Palsy**
congestive heart failure	**PDD-NOS,**
PDA ligation	**Moderate Autism**
Two Holes in Lung	**Mild MR**
Cholestatic Jaundice from the TPN	**Down Syndrome**
Anemia	**Cerebral Palsy**
Sepsis	**ADHD**
Necrotizing Enterocolitis	**ADHD**
GERD	**OCD**
Retinopathy of prematurity	**Oppositional Defiance Disorder**
Astigmatism	**Emotional Disturbance**
Nonverbal	**“Mildly Retarded” (ya, I was told that)**
PDD-NOS	

Autism spectrum disorder
Pyruvate Dehydrogenase Complex Deficiency type 'x'
Non-verbal
Autistic
Sensory Processing Disorder
Severe Autism
Speech Impairment-nonverbal
ADHD
Autism
Pica
Autism Moderate
Intellectual Disability
ODD
ADHD
Prematurity
Chronic Lung Disease
Bilateral Grade IV IVH
Hydrocephalus
Cortical Vision Impairment
Optic Nerve Atrophy
Low Vision
GERD
Failure to Thrive
Dysphagia
Global Developmental Delay
Scoliosis
Epilepsy
Spastic Quadriplegic Cerebral Palsy
Autistic
Sensory Perception Disorder
Autism spectrum disorder
Sensory Processing Disorder
Auditory Processing Disorder
Receptive Expressive Language Delay
Severe Autism

Mixed Seizure Disorder
Self-Injurious Behavior
Non-verbal
PDD-NOS
ODD
Autism
Epilepsy
Sleep Dysfunction
Low M uscle
Btone(wears bces on legs)
Constipation
Autism
Severe Spastic Quadrapalegia Cerebral Palsy
PDD-NOS
Autism
Autism w/ multi/handicapped (educational diagnosis)
Hypoplastic Left Heart Syndrome
Hydrocephalus
Elhers Danlos Syndrome
Cerebellum Agenesis
Hypoplastic Brainstem
Microcephalic
Mentally Challenged
Legally Blind (cortical blindness)
Epileptic
Schizoid Affective disorder
Schizophrenia
Spectral Autism
ADD
Spina Bifida
GERD
Hydrocephalus
spinal syrinxes
Neurogenic Bowel & Bladder

Paraplegic (paralysis at T12 level)	**Autistic**
Full Oral Dysphagia	**Lower Cognitive Functioning**
Severe Developmental Delay	**Autism**
Refractive Epilepsy (Lennox-Gastaut Syndrome)	**ADHD**
Pseudo Strabismus	**Tourette's**
Autism/moderate	**Autism**
Insomnia	**PDD-NOS**
behavior problem in child	**OCD**
Sensory Processing Disorder	**ADHD**
ASD	**Generalized Anxiety**
ADHD	**Autism**
Overanxious Disorder	**ADHD**
ADHD	**Young Child with Developmental Delays**
OCD	**ADHD**
Asperger's	**Anxiety Disorder**
Autism	**Mixed Expressive-Receptive Language Disorder**
Bipolar	**Autism spectrum disorder**
Depression	**Eczema**
Anxiety	**ADHD**
Schizophrenia	**Speech**
ASD	**Learning Disabilities**
ADHD	**Anxiety**
ODD	**High Functioning Autism**
CNS Disorder NOS	**Asperger's**
Apraxia	**Dyspraxia**
Dystonia	**ADHD**
Cognitive Delays	**Hearing Loss**
Multiple Disabilities	**Chromosome Disorder**
Hyper Plastic Left Heart Syndrome	**Heart Murmur**
3C Syndrome (cardio, cranium, cerebellum)	**Intellectual Disability**
Clubbing on toes and fingertips	**Asperger's Autism**
Non-Verbal	**Schizoid Disorder**
Gastronomy tube	**Social Anxiety**