A QUALITATIVE INQUIRY: PARENTAL APPROACHES AND EXPECTATIONS, WHAT

ROLE DOES DISABILITY PLAY?

by

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A Dissertation Submitted to the Faculty of the

DISABILITY & PSYCHOEDUCATIONAL STUDIES

In Partial Fulfillment of the Requirements

For the Degree of

DOCTOR OF PHILOSOPHY
WITH A MAJOR IN REHABILITATION

In the Graduate College

THE UNIVERSITY OF ARIZONA

2017

THE UNIVERSITY OF ARIZONA

GRADUATE COLLEGE

As members of the Dissertation Committee, we certify that we have read the dissertation prepared by Gabrielle Ficchi, titled A Qualitative Inquiry: Parental Approaches and Expectations, What Role Does Disability Play? and recommend that it be accepted as fulfilling the dissertation requirement for the Degree of Doctor of Philosophy.

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Acknowledgements

I would like to thank my dissertation committee, especially my committee chair Dr. Shaw for giving their time, support, and feedback. You have helped me to grow as a researcher and as a clinician.

 I would also like to thank my family. I would not be where I am today personally or professionally without your belief in me. You kept me going through the hard times and were a constant source of support. To my parents, you have always taught me that anything is possible and to embrace who I am, it is because of you that I developed this passion. I cannot thank you enough for your love and support. I love you all

To my friends, it has been a long road and your constant support has meant the world to me. You have supported from beginning to end on this journey. Thank you for always being there, I love you.

To my shake a leg and empower families, this all started with a dream and it is because of those programs and all of you that my dream has now become a reality. Thank you all so much for helping me to continuously fuel my passion for this work and making this process so much more meaningful. I would not be where I am today without all of you.

I also want to thank my husband Matt for being so patient, understanding and loving while I followed my passion to complete this process. I know it has been a long tough journey with many sacrifices. I could not have done it without you. Love you always

Dedication

I dedicate this dissertation to all the parents raising children with disabilities; I thank you for all your love, support and guidance. You are the best advocates for your children.

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ABSTRACT

Parenting a child with a disability is a unique experience, and both parents and children need to find the most effective parenting strategies. The purpose of this qualitative study is to gain a better understanding of the experiences associated with raising a child who has a disability. Specifically, this study examines what factors parents feel influence them in making decisions about their child and the expectations they have for them. In addition, it assesses how parents perceive they have modified their childrearing approaches and expectations for their child with a disability. To collect qualitative data, the investigator used narrative inquiry. This methodology was appropriate as eliciting specific stories and examples from participants allowed the team to capture the authentic experience of each one.

The primary investigator collected qualitative data through multiple interviews with parents who have children with disabilities. For purposes of this study, sampling methods were a mix between convenience and non-probability sampling. Parents included were those of children whose disability is primarily physical. The researcher conducted a semi-structured interview to examine the feelings, thought processes, challenges and overall life experience surrounding parenting a child who has a physical disability. Data was analyzed using a "constant comparative" method whereby the researcher constantly compares within the study the data being collected.   Periodic review of the data, as well as summaries, helped identify trends warranting further analysis.

Overall, the results of this study indicate that parents and families perceive that they have needs that are not being met, empowering them to make certain parenting decisions. Based upon these perceptions, it would appear that there is a need for change in the types of services and information parents are receiving. While medical support is necessary, parents are also expressing a need for more practical forms of assistance.. This study explores several ways in which rehabilitation professionals might implement changes in order to accommodate these needs. Families whose children have disabilities expressed both a strong desire to provide the best possible care. What appears to be currently lacking is sufficient education and emotional support to channel their loving energy into setting higher expectations for their children, knowing how to effectively plan for and reach milestones, while being confident enough in their child's abilities to afford them opportunities to take control of their own lives.

CHAPTER ONE

INTRODUCTION

Parenting a child with a disability is not always an easy task. Each disability comes with its unique set of challenges, and both parents and children need to find the most effective ways to deal with them. Sanders (2006) found that parents often assume added responsibilities in order to make their disabled child's life as easy as possible, and that parents do not require as much accountability or behavioral autonomy from them as they would a typically-developing child.

Research indicates that parents and care providers of children with disabilities may overprotect these children with the intent of shielding them from harm; however, this emphasis on safety also limits these children's exposure to difficult situations, preventing them from learning from failures and experiencing, the increased sense of self-efficacy that comes with surmounting challenges. When caring for a child with a disability, parents, as well as others within the child's support system, tend to shift their focus more heavily onto managing various aspects of the disability rather than on the child's overall quality of life (Sanders, 2006).

Statement of the Problem

Traditionally, the treatment of children with disabilities tends to emphasize management of the physical aspects of the disease, and physicians measure treatment efficacy primarily by means of physical improvement. However, several studies (Hartlage and Green, 1972; Cappelli, McGrath, MacDonald, Katsanis, & Lascelles, 1989; Homebeck et al. 2002; Aran & Shalev, 2007; Rybak, et al., 2016) have shown that this approach to disability management tends to lead to overprotection rather than fostering autonomy and encouraging independence. Though well intentioned, this overprotective approach can promote delays that affect many if not all areas of a child's life, including education and employment. As a result, overprotected children may fail to

develop the necessary behavioral, social, communicative, functional, occupational, and basic academic skills necessary to succeed in school, live independently and lead full, well-rounded lives.

There is ample evidence that finding an appropriate balance when parenting a child with a disability is challenging for families (Aran and Shalev, 2007); however, there is a need for researchers to explore this area further to develop new approaches towards effective parenting strategies for improving family interactions and involvement with their children (Holmbeck, et al., 2002). For children of any ability level, access to necessary opportunities to develop behavioral autonomy is vital to success. Consequently, it would appear to be important to encourage parents, and other individuals interacting with the child on a daily basis, to learn specific styles and practices that nurture the skills required for independence and maturation.

While researchers continue to explore parenting children with disabilities, most inquiries up to this point have utilized quantitative approaches. Such approaches attempt to explain phenomena according to numerical data analyzed by means of mathematically based methods, especially statistics. While these approaches have shown a relationship between parenting style and social maturity in disabled children, they have not taken the research further to address the question as to why overprotection occurs and what factors contribute to it. In order to obtain a deeper understanding of this issue, additional research should examine the social structures and individual experiences associated with parenting a child with a disability.

Brief Overview of the Literature

Research has shown that parenting style is one of the most important family variables in a child's psychosocial development. Cappelli et al. (1989) found a number of significant

correlations between overprotection and poor psychosocial functioning in children with cystic fibrosis. Similarly, Hayden et al. (1979) and Holmbeck et al. (2002) found that overprotection levels were higher for parents of children with spina bifida and this was associated with lower levels of preadolescent decision-making autonomy, which, in turn, was associated with more externalizing problems. These findings are consistent across the available literature, regardless of the type of physical disability the child has. Adults treat children with disabilities differently from their peers and, as a result, children with disabilities do not have the same life experiences. In their correlational study of children with cerebral palsy, Aran and Shalev (2007) found that overprotection had a far greater impact on the psychosocial aspects of quality of life than any other factors associated with disability. An autonomy-allowing parenting style, in contrast to a controlling and rejecting parenting style resulted in children having improved mental health, higher self-esteem, better behavior, and fewer social and emotional limitations.

Clinical experiences have suggested that certain attitudes and child-rearing practices, such as being too overprotective, may negatively affect academic achievement. Hartlage & Green (1972) conducted a correlational study on children with epilepsy. They found several variables that contributed to a student's social and academic success were correlated with the attitudes of his or her parents and educators. Attitudes that correlated significantly with low levels of social development and academic performance involved overprotective child-rearing practices and lower levels of autonomy. Furthermore, students who experienced higher levels of overprotection had lower scores overall on academic performance. The effect of environment on a child's development of adaptive cognitive skills and academic success merits further investigation. For children of any ability level, having opportunities to develop behavioral

autonomy is vital to success. Based on the literature, it may be helpful for parents to learn specific styles and practices that nurture the skills required for independence and maturation.

Purpose

The purpose of this qualitative study is to gain a better understanding and help inform the development of new theory regarding how and why parents make decisions and develop parenting styles that overprotect versus allowing autonomy, and gain a clearer understanding of how such decisions affect children long term. The available literature has established a correlation between parenting style and social maturity and the negative impact it has on children with disabilities. However, the literature currently does not address the question of *why* parents make parenting choices that overprotect their child and limit their development of autonomous functioning. The results of the present investigation will provide a better understanding as to why this correlation exists and help professionals find new ways to encourage parents to allow their child more independence. With added support, families may learn to embrace positive change and ensure their child has opportunities to cultivate his or her social skills. This study explores this phenomenon from a new vantage point by using a qualitative approach, with the goal of developing novel theory that can provide insight into this otherwise poorly understood process.

Significance

This dissertation will offer valuable contributions to the current body of literature on parenting styles as it relates to children with physical disabilities. The purposes of this dissertation are: (a) to form a comprehensive understanding of the existing rese arch on parenting styles as it relates to disability; (b) to expand this research by applying a qualitative approach to examine the social structures and individual experiences as well as the attitudes and perceptions associated with

parenting a child with a disability; and (c) to provide a basis of information for new theory development. This will permit analysis of the larger process, and a greater understanding of the bigger picture over time. Ample evidence documents that parental overprotection causes delays in the development of autonomy and social maturity (e.g. Cappelli et al., 1989; Aran and Shalev, 2007; Holmbeck, et al., 2002). However, most research in this area to date has used a correlational methodology and questionnaires to obtain data. Questionnaires yield statistical data; however, they do not afford the opportunity to delve into *why* certain dynamics exist within a family or the beliefs behind parenting decisions. The researchers conducting those studies did not talk with the families and hear about their experiences and perceptions firsthand, which would have produced richer and more authentic data that could then be used to better inform the design of interventions that support parents in making childrearing decisions that are most beneficial to their children with disabilities. While the current research has documented a relationship between parenting style, behavioral autonomy, and social maturity in children with physical disabilities, it has not uncovered the reasons for this phenomenon, possible solutions, or factors that contribute to it.

The novel methodological approach utilized in this dissertation will provide a deeper understanding of the dynamics associated with raising children with disabilities, which will in turn address the 'what', 'how' and 'why' associated with the choices parents make in raising their children with disabilities. Further exploration of the area of social maturity and parenting as it affects children with disabilities, will help to enhance the rehabilitation experience. Rehabilitation professionals may gain useful knowledge and insight as to how best help parents and their children. In turn, this will ensure the child has the opportunity to reach his or her full potential. This research will explore how and why parents make decisions about parenting style; this will provide a better understanding of family dynamics and investigate whether the process of parenting a child with a

disability is static or dynamic in nature. The deeper we understand these constructs the better equipped we will be to elaborate on existing theoretical frameworks to cultivate new concepts.

Research Questions

This dissertation will explore parenting styles and attitudes as they relate to a child with a physical disability. Three questions will guide this investigation:

(a) What factors do parents feel influence them in 1) making parenting decisions about their children with disabilities that involve questions about autonomy vs. protection; and/or 2) the expectations they have for their children?

(b) How do parents perceive that they have modified their childrearing approaches and expectations for their children with disabilities?

(c) How do parents feel they could have been better supported through the process of raising their children with disabilities?

<div align="center">**Terms and Definitions**</div>

Autonomous Functioning

In recent literature, concepts referring to a child's ability to be more independent or display autonomy have continued to define this overall behavioral construct. Research suggests that behavior that is more autonomous has numerous positive outcomes for children as they grow and express increasing levels of maturity (Roth, Assor, Kanat-Maymon, & Kaplan, 2007). Ryan & Deci (2000) define autonomy as regulation by the self. When autonomous, individuals experience their behavior as self-endorsed and congruent with their values and interests.

Autonomy encompasses a variety of constructs, including maturity, social preparedness, independence and self-reliance. These characteristics, in turn, are influenced by an individual's

willingness, determination, insight and the extent to which he or she is dependent upon others (Ryan, La Guardia, Solky-Butzel, Chirkov, & Kim, 2006). For purposes of this dissertation, these constructs as a whole will be referred to as autonomous functioning. Autonomous functioning refers to behavioral autonomy, social maturity, independence and social development.

Social Maturity

Maturity is defined as an individual's ability to respond to their environment in an appropriate manner; this response is generally learned rather than instinctive. Maturity also encompasses being aware of the correct time and place to behave in a certain manner and knowing when to act appropriately, according to the circumstances and the culture of the society one lives in (Wechsler, 1950). When an individual is socially mature, they are showing behavior that is in accord with standards and the norms for a person of that age. According to Kellmer (1951),

> "Social Maturity is manifested by the extent to which an individual is able and willing to conform to the customs, habits and standards of behavior prevailing in the society in which he lives. Furthermore, by the degree to which he is able to do so independently of direction and guidance; and by the extent to which he participates constructively in the affairs and conduct of his community." (p. 115)

The environment in which children grow up is an essential component in helping them to develop and mature properly in a social setting. Children need the opportunity to nourish the maturation process and, in turn, learn to adapt to certain social situations by acquiring new skills and behaviors (Kellmer, 1951).

Parenting Style

Parenting style is a predominant factor in socialization because it is within the family circle that social learning begins and the first social contact is established. (Kellmer, 1951) Several characteristics determine the processes through which parenting style influences child development, including but not limited to: the values and goals parents have in socializing their children; the parenting practices they employ and the attitudes they express toward their children. Different parenting styles affect a child's degree of socialization and maturity. A sign of good parenting and social maturation is a child who is "instrumentally competent", which Darling (1993) describes as "children who were the products of homes in which parents were warm, established clear, rational guidelines, allowed the child autonomy within those boundaries, and clearly communicated both their expectations and the reasons behind them." (p.7)

In the face of disability, parents utilize different dimensions of parenting to cope with the situation. One such dimension is parental control and restriction versus allowing autonomy: parental control refers to extensive regulation of the child's behaviors and actions, autocratic parental decision-making, overprotection, and giving instructions to the child about how he or she should think or feel. The presence of a physical disability often causes parents to be more restrictive and allow their child less autonomy (Aran, & Shalev, 2007). Although an overprotective parenting style often comes from a place of love and the desire to keep a child out of harm's way, there are many unforeseen negative consequences.

Miscarried Helping:

The concept known as 'miscarried helping' can be defined as well-intentioned support attempts that fail because they are excessive, untimely, or inappropriate, as sometimes occurs

between parents and their chronically ill children or adolescents. Anderson and Coyne (1991) used this theory to help understand how interpersonal conflict emerges in families of children with a chronic illness. They highlight how good intentions on the part of caregivers result in interpersonal conflicts between youth with chronic health problems and their parents. The result is further separation and discourse among the children and their parents, while simultaneously putting the child's health at greater risk. Miscarried helping involves an investment on the part of the caregiver to be a good helper, coupled with a belief that their help will result in better outcomes for the child. The help from the caregiver is less about what the child wants and needs and more about what the caregiver thinks is best (Harris, 2006). Parents may intend their behaviors to be supportive but in the end, they may generate conflict. The child may not have the necessary opportunities to foster independence; therefore, they do not reach certain social or behavioral milestones that are essential for typical development.

Independence

Traditionally, independence is defined as a person's evolution from a state of dependent childhood to an independent adult identity based on the achievement of developmental milestones (Valentine & Skelton, 2007). Oftentimes disability tends to be understood as reliance on others, and as a result, these individuals are not seen as independent (Friedman & Owen, 2017). The disability studies community on the other hand, examines disability through a different lens. this community is comprised of individually who look at the meaning, nature, and consequences of disability as a social construct. This discipline prioritizes the lived experiences of individuals with disabilities in practical terms with the focus on improving quality of life and civil rights for individuals with disabilities (Karus, 2008). As such, the view of. independence shifts to seeing it as a social construct well rather than as a physical characteristic. Consequently, one's physical

abilities or developmental milestones do not determine the presence or absence of independence. They use the term 'independent' to mean someone who can do everything for themselves, but to indicate someone who has taken control of their life and is choosing how that life is led (Thomas, 2004).

Theory Development

The theories above lend themselves to helping explain why parents may choose an overprotective parenting style as opposed to encouraging social maturity. The aim of this dissertation is to use grounded theory with the intent of developing new theories that may help explain this phenomenon as it relates to disability and the parenting experience. Grounded theory is a subjective research approach created by Glaser and Strauss in the 1960s. The self-characterized motivation behind grounded theory is to create a hypothesis grounded or established in perception (Strauss, 2006). Grounded theory refers to a set of systematic inductive methods for conducting qualitative research aimed toward theory development. The term grounded theory denotes dual referents: (a) a method consisting of flexible methodological strategies; and (b) the products of this type of inquiry. Increasingly, researchers use the term to describe methods of inquiry for collecting—and in particular analyzing—data. The methodological strategies of grounded theory are aimed at constructing middle-level theories directly from data analysis.

Grounded theory has considerable significance because it: (a) provides explicit, sequential guidelines for conducting qualitative research; (b) offers specific strategies for handling the analytic phases of inquiry; (c) streamlines and integrates data collection and analysis; (d) advances conceptual analysis of qualitative data; and (e) legitimizes qualitative research as scientific inquiry. Grounded theory methods have earned their place as a standard social research method and have influenced researchers from varied disciplines and professions (Strauss, 2006).

Grounded theory is a perplexing iterative process. The exploration begins with the ideation of generative issues, which helps to control the examination but are not planned to be either static or limiting. As an exploratory method, grounded theory is particularly well suited for investigating social processes that have attracted little prior research attention, where previous research is lacking in breadth and/or depth, or where a new point of view on familiar topics appears promising. (Milliken, 2010).

Researcher Identity

I hold several levels of interest in examining parenting styles as they affect children with disabilities. To begin, I have a physical disability myself. I was born with cerebral palsy, a condition or group of several disorders that can have an impact on the brain and the nervous system. It can affect many different body processes, such as movement, thinking, learning, speech, vision and hearing. I consider myself lucky as I fall somewhere in the middle of the spectrum in terms of abilities. I have typical cognitive function but I cannot walk or use my left arm. While my disability has presented challenges, I continue to thrive on my ability to adapt to them and assert my independence.

Growing up, my parents instilled in me the confidence I needed in order to know that I could do what I wanted to do in life. My twin sister and I were my mother's first two children and my mother will be the first to tell you that she did not know anything about raising a child with a disability—she raised me as she would any other child. This mindset illustrates the premise of how I grew up and demonstrates the viewpoint that has guided my thinking from a young age. Until I became older, I was not aware that I was different.

It is very difficult for most parents to learn their child has a disability, and when they do, they tend to want to shield their child from additional hardship. Many parents feel utilizing an

overprotective parenting style is best; as a result, their children are not given the same opportunities to learn and grow as their peers. While I understand this comes from a place of love, I have seen firsthand how detrimental it can be. From growing up and seeing others who had a disability similar to my own, to now working in the rehabilitation field, I have seen how children learn to rely too heavily on their parents and turn to them to make every decision. From my own research and from what I have been told anecdotally, parents often believe that when they make decisions for their child, they save them from failure, hurt and disappointment.. In reality, failure is a part of life and something we all learn from as we grow and mature. There is dignity in taking risks, and it is how we respond to failure that is most telling. Teaching children to trust themselves will empower them to take risks. Whether the outcome is good or bad, they will learn from it, just as their able-bodied counterparts do.

My knowledge is based on what I have experienced as well as previous research I have conducted. In my opinion, a key aspect missing from the current literature is firsthand accounts from the parents' perspective. This knowledge gap is what ignites my passion and drives me to conduct research in this area. I want to better understand this unique experience from the parents' point of view so I can best serve the families and children I work with. While conducting the research, I have to be careful not to let my own experiences and biases influence the perceptions I have of the participants. As a part of the study, I seek external validation for my perceptions, interpretations and theories on parenting a child with a disability in order to ensure I accurately report and interpret information obtained from study participants.

My personal experience is both a strength and a weakness in carrying out this study. On one hand, I hope to make a unique contribution, as I believe that I will be able to capture the participants' stories more vividly and be more sensitive to the difficult subject matter. My

disability is likely to help the people I interview trust me without invading their story; I have been

there and can empathize with their situation, though our specific experiences may differ.

On the other hand, my ability to put myself in participants' shoes could be confused by my own

perception of the situation based on my experiences. I may also be tempted to go beyond my role

as a researcher and become more of a helper; I recognize that I sometimes care too much in

certain situations. I need to balance my relationships in order to ensure I conduct valid research.

Dissertation Format

This dissertation follows a traditional five-chapter format. Chapter one (the current

chapter) is an introduction that explains parenting styles and the effects of parenting approaches

on children and addresses the importance of this topic. The introduction also includes a brief

overview of the literature regarding the purpose of the studies and research questions, and a

description of how the dissertation is organized. Chapter two is a literature review on parenting

styles related to children with disabilities. Chapter three describes the methods and includes a

discussion of the participant samples, methodologies, and analysis strategies used in the study.

Chapter four details the study findings and results. Finally, chapter five includes a discussion of

the significance and impact of the findings, as well as limitations of the study. Chapter five

draws conclusions from the results in order to discuss how this information can help inform

practices when working with young adults and adolescents with physical disabilities.

CHAPTER TWO

LITERATURE REVIEW

The Impact of Parenting Style on the Social Development and Maturity in Children with Physical Disabilities

This chapter is a synthesis of the literature that examines parenting styles and attitudes as they relate to children with physical disabilities, and how they affect the social maturity and behavioral autonomy of the children. The author will review the current research on parenting style as it relates to disabilities, the family dynamics that are created, and the impact parenting styles have on quality of life and the individual children's economic welfare. Exploring the available research in these areas with the intention of understanding the entirety of the families' experiences with disability will broaden our understanding of parental attitudes and how or why they make decisions that concern their children. This in turn will help in forming recommendations for future research and the provision of a more effective rehabilitation experience that will aid in promoting maturity and independence.

Method

Broad literature searches for published peer reviewed research articles on social maturity, autonomy and parenting style as they relate to disability were completed. Multiple databases were queried, including the University of Arizona's online library, Academic Search Complete, ERIC, PsycINFO and Google Scholar. Essential search terms included *social maturity, parenting style, parenting attitudes, disability*, and other terms related to disability including *impairment, disabled, disabled children,* and *children with disabilities*. In addition, the researcher performed searches using the term *disability* combined with *family dynamics, family stress, siblings* and

family relationships. The results of the initial broad search were narrowed to include studies

examining individuals with only physical disabilities, and exclude those with learning disabilities

and cognitive impairments. Searches were not limited by study design. After articles that

addressed the topics of interest were found, others were identified by examining the reference

lists therein and searching relevant rehabilitation journals manually.

After exclusion of all literature reviews, 35 primary research articles remained. Abstracts

were reviewed and a select number of articles were read in full to identify those most relevant to

the research questions addressed here. Most of the research examined was current at the time of

writing; however, several older articles were included to illustrate the evolution of several pivotal

findings. In addition, the latter articles provide important background information related to the

main concepts discussed in this review, and details as to how contemporary researchers have

built upon earlier findings to make advancements. Meanwhile, the more recent studies provide

not only continuing evidence of parental impact on children with disabilities, but they also

provide further justification for additional research in this area with respect to how disability

impacts families, rehabilitation as a profession, and where future efforts should be concentrated.

Synthesis

Disability

The Oxford Dictionary defines disability as "a physical or mental condition that limits a

person's movements, senses, or activities." The common perception of disability has been that of

a biological or psychology inadequacy, or that of a tragedy,

rather than a social phenomenon (Kraus, 2008). On the contrary, disability researchers, advocates

and scholars have fought to challenge these ideas as this framework is disempowering to the

disability community. Three perspectives help to explain and contextualize the disability

experience, the medical and social model of disability and the independent living philosophy.

The medical model of disability takes the "individualistic" perspective on disabilities and

the people that have them. According to this model, the condition is seen as a deficiency or

abnormality. It views disability as a problem and the responsibility to fix it falls on the

individuals themselves (Goodley, 2016). The individual with the disability is the focus of the

intervention and the agent of that intervention is the professional. This professional is given all

the power and oftentimes feeds into the common stereotypes of people with disabilities,

including that they are in need of their services or they are "helpless" (Vash, 2003).

The social model on the other hand shifts its focus to society and the environment. In this

model, the impartment is seen as a difference as opposed to an abnormality (Swain et. al., 2003).

The disability itself comes from the interaction between the individual and society, meaning that

society and the environment should be adapted to the individual,not the other way around. It also

takes more of a societal approach rather than the responsibility falling only on the individual.

Disability is addressed by the disabled individuals as well as peers (Goodley, 2016).

This model recognizes social discrimination as the most significant problem experienced

by persons with disabilities. The social model reinforces the idea that disability is largely a

social construct. Socially, some impairments create great disadvantage or social stigma for the

individual, while others do not. We as a society have conceptualized disability based on our

stigmas and preconceived notions. (Meekosha, & Shuttleworth, 2016).

Recent disability researchers and activists have continued to shift their thinking in

defining disability to help disabled individuals perceive themselves and their disability more

accurately, believe in themselves and their capabilities, and have the confidence to make their

own decisions. This paradigm is known as the independent living philosophy, and is rooted in deeply held values and beliefs about how people with disabilities can acquire and maintain their personal independence. It is a unique approach that evolved out of the disability community, and emphasizes the cultivation of autonomy and self-control (Usiak, 2004).

Funded through the rehabilitation act of 1978, centers for independent living provide an environment that is consumer-controlled and focuses on how individuals can reach their full potential and live a life infused with empowerment, autonomy to make their own decisions, dignity and independence (Uisak, 2004). These last two perspectives regard disability as a normal aspect of life, and challange the notion that persons with disabilities are in some inherent way "defective." Most of the literature published on this study topic is derived from the medical model perspective; The researcher hopes to add to these findings from a social model and independent living standpoint and provide recommendations that incorporate these viewpoints moving forward.

Parenting Styles

Many studies focusing on parenting styles expand on concepts originally conceptualized in the work of Diana Baumrind in the 1960s and later in the work of Darling and Steinberg in the 1990s. Baumrind's (1966) research on parenting styles focused on two dimensions: (a) control versus demandingness, which focused on the parents' control of the children's maturity and higher levels of supervision and discipline; and (b) responsiveness, which, on the other end of the spectrum, focused on fostering independence, self-assertion, and maturity, while continuing to support the child.

Although substantial support for Baumrind's classifications remains, views toward parenting styles have evolved over time. The more contemporary studies of Darling and

Steinberg (1993) distilled parenting styles down into four groups that researchers still use today in order to classify parenting style. The first is the *authoritarian style,* where parents operate under high levels of control and low levels of responsiveness. Conceptually, parents operating within this style have high expectations for their children and exert high levels of control over them, expecting that they conform to parental rules and directions. In addition, they exhibit low levels of responsiveness to their children or their expressions of individuality. While some children function better under high levels of structure, some may also rebel or distance themselves from parents with age. The second is the *indulgent or permissive style*, where parents have a low level of control and high responsiveness rates. This style is categorized by a warm and loving relationship between parents and their children. However, having lower levels of control over their children or their actions can manifest in lower expectations of behavior and a lack of guidance or structure. The third, the *neglectful style* is when parents utilize low levels of both responsiveness and control. These type of parents tend to provide necessities for their child but are emotionally uninvolved in a child's life. This can cause serious abandonment issues or lead to feelings of resentment. Lastly, the *authoritative style*, is where parents utilize high levels of control and high levels of responsiveness. In most cases, this type of parenting style is seen as ideal. This type of parent hold high expectations of the child's behavior while allowing them opportunities to be involved in the decision-making process. While parents still set rules, they also give children the opportunity to learn about cause and effect, self-sufficiency and decision-making skills (Darling & Steinberg, 1991)

Contemporary researchers have used, and continue to use, these four classifications to help assess how parenting styles influence child development with regard to social competence and maturity (Prevatt, 2003, Bornstein & Bornstein, 2007, Hauser & Grych, 2013). Prevatt's

(2003) findings suggested that the authoritative parenting style worked best to accommodate a child's developmental needs. While researchers now have a more complete understanding of how certain parenting styles affect children's development, many early studies focused only on the white middle-class children and their families. Bornstein and Bornstein (2007) questioned how children from diverse backgrounds develop under different types of parental guidance. They found no significant differences among cultural groups; parenting styles were shown to have the same impact across cultures. However, disability was not included as a sub-group in that study, and further research, including the present study, will expand upon these culture-related findings and examine how disability can influence parenting style and social competence. Bornstein and Bornstein (2007) found that, "In many situations, adoption of a flexible and warm authoritative parenting style is most beneficial for a child's social, intellectual, moral and emotional growth" (p. 25).

Over the past few years, many researchers have advocated for the authoritative parenting style. Hauser and Grych's (2013) findings support this style over others. Using surveys, the researchers found that this style blends warmth with support that is flexible enough for a child to develop distance, independence, autonomy, and appropriate social skills. When parents are able to balance their levels of control and responsiveness, their children develop higher levels of social maturity. The children also foster greater competence in their peer relationships and have greater emotional well-being than children whose parents adopt a more protective or indulgent style which in the case of parents whose children have disabilities might include an overprotective style.

Egeli, Rogers, Rinaldi & Cui (2015) found that parents who can communicate social expectations and encourage continued social development as the child ages are better able to

maintain a parent-child construct that includes warmth, structure and support autonomy. Research continues to suggest that parenting style influences the social development of children. Similarly, it seems reasonable that the environments that parents create for their children will play a part in development or underdevelopment of their social competencies (Egeli & Rinaldi, 2016). As detailed in the following section, a number of studies have examined parenting styles as they relate to children with physical disabilities. Researchers have explored how parents of these children utilize a more authoritative, overprotective parenting style, and how doing so can negatively affect the children's social development and maturity

Overprotective Parenting Style Related to Disability

When caring for a child with a disability, parents tend to focus less on their child's overall quality of life and more on their physical condition (Aran & Shalev, 2007). Traditionally, the treatment of children with disabilities has focused on physical aspects of the disease: If the child's physical condition improved, doctors considered the treatment effective. However, a number of studies (Hartlage and Green, 1972; Cappelli, McGrath, MacDonald, Katsanis, & Lascelles, 1989; Homebeck et al. 2002; Aran & Shalev, 2007; Rybak, et al., 2016) have found this approach to be problematic because parents tend to focus primarily on physical improvements, tending to overprotect their child and stunting development in other areas.

The effect of the environment on children's development of adaptive cognitive and social skills merits exploration. The present study will expand the investigation into this area by examining the type of environment created by a child's parents. Over four decades ago, Hartlage and Green (1972) conducted an influential correlational study on children with epilepsy. Using questionnaires, researchers found that parental attitudes directly correlated with several variables related to social achievement, defined as how well they progressed through in development of

their social skills. The attitudes that most significantly positively correlated with social

development involved the strictness of child-rearing practices. Furthermore, socialization was the

aspect of development that correlated to the greatest extent with parental attitudes.

Hayden, Davenport, and Campbell (1979) studied children with spina bifida and

investigated the effects of parenting styles on their social maturation. The researchers wanted to

expand on earlier findings, which showed the impact of overprotective parenting and on

children's abilities to make decisions on their own. The authors used a correlational design and

questionnaires to conduct the study. They found that parental overprotection was high in children

with spina bifida and it was associated with lower levels of preadolescent decision-making

autonomy, which was, in turn, was associated with more externalizing problems. Interestingly,

although they were of normal intellect, adolescents with spina bifida seemed to take little

responsibility for independent tasks they were physically capable of preforming. "Parental

attitude is an important determinant of when social skills will be mastered by a child. Several

parents still believe their teenagers are too immature or physically handicapped to handle

independence, certain social interactions or sexual behavior" (Hayden et al., 1979, p.10).

A decade later, Cappelli, McGrath, MacDonald, Katsanis, and Lascelles (1989) set out to

further examine the relationship between parenting styles and the psychological functioning of

children with and without cystic fibrosis (CF). The authors conducted a correlational study using

a series of questionnaires to collect data; these were given to parents and children in both the CF

and control groups of healthy participants. Researchers investigated whether there was, in fact, a

significant relationship between parental overprotection and psychological maladjustment in

children with CF. Interestingly, in the sample of children without CF, poor psychosocial

functioning was highly correlated with a lack of proper parental care. The authors concluded that

parental overprotection and level of care play an important role in the psychological functioning

of children with disabilities.

These finding are consistent across current literature, regardless of the type of physical

disability. Parents treat children with disabilities differently, causing them to experience

postponements in their development. Homebeck et al. (2002) set out to examine the associations

between parental overprotectiveness, behavioral autonomy, and psychosocial adjustment in

children with and without spina bifida. The researchers aimed to expand on the findings from

previous studies that showed the relevance of overprotective parenting and its effects on

children's abilities to make decisions for themselves. They addressed the area of overprotective

parenting and its effects on behavioral autonomy that had not previously been widely studied

using a control group of to compare children with disabilities directly to their able-bodied peers.

This correlational study used questionnaires and observational measures to assess parental

overprotectiveness, as well as reports of behavioral autonomy from parents, children and

teachers, to see how well the children had adjusted psychosocially for their particular stage of

development. The samples were matched evenly between children with spina bifida and those

without spina bifida. The results indicated that there was a significant relationship between

parents being overprotective and children with spina bifida showing less behavioral autonomy.

While the same was true for the control group, the overprotective parenting approach had an

even greater impact on the children who had disabilities.

In a follow-up study, Sanders (2006) used a correlational design to show that parenting

style is one of the most important family variables in children's psychosocial development and

"when parents overindulge or overprotect the special needs child, they take away the experiences

which enable the child to be successful in life" (p.180). The consequences of overprotection

include lower levels of self-esteem, feeling less capable and reduced opportunity for growth

(Sanders, 2006).

That same year, Shogren (2006) performed a quantitative study focused on the social

aspects of development that are rooted in the environment in which children with disabilities are

raised. He found that the parent-child relationship was a critical influence on the development of

autonomy and social maturity in young children. As such, in order to support the development of

those skills, parents must give children with disabilities the opportunity to function

independently. The author states, "It is imperative that parents respond to young children's early

attempts to exert control over their environment. When such attempts go unrecognized, children

may develop, very early on, diminished perceptions of their ability to exert control and engage in

actions to achieve desired outcomes" (p. 4). Several studies followed that helped to validate and

expand upon these findings (Aran & Shalev, 2007; Rapin, 2008).

Aran and Shalev (2007) conducted a correlational study on children with cerebral palsy in

order to examine their quality of life. The authors found that autonomy allowing and accepting

parenting styles—in contrast to controlling and rejecting parenting styles—reflected improved

mental health, higher self-esteem, better behavior, and fewer social and emotional limitations. In

addition, "The impact of parenting style on psychosocial aspects of quality of life was far greater

than other factors associated with disability." (p. 57).

Rapin (2008) also examined the quality of life of children with physical disabilities. This

is one of very few quantitative studies that incorporated the children's perspectives. The children

reported that the quality of their lives had more to do with their parents' management style than

with the severity of their disabilities. Surveys completed by the children revealed that their

parents' acceptance of their disability and willingness to foster autonomy and independence

helped them most in everyday situations and in social environments. A separate study by Ahn &
Lee (2016) supported these finding by expanding upon the idea that parents of adolescents with a
disability or chronic illness may perceive their children as being more vulnerable and tend to
over-protect them and be over-involved in their children's lives, because these parents perceived
that their children required a higher level of vigilance. Over-involvement included negative
parental style, and more negatively affected self-concept and school adjustment in adolescents
with chronic illness compared with healthy adolescents (Rybak, et al., 2016). Excessive parental
control and protection link to an increase in negative psychological symptoms in these
adolescents.

      Together, these findings illustrate how parenting styles profoundly affect the social
maturity of children with physical disabilities. In addition to how parents treat their children with
physical disabilities, their attitudes towards them can affect the dynamics of family structure.
Those intricacies within the family also influence the child's social maturity and psychosocial
development.

Family Dynamics and Disability

      Families experience disabilities differently; however, there are some common challenges.
These include such things as relationships between the children with disabilities and their able-
bodied siblings, how the parents react to the children's disabilities, and how the children are
treated within their family. Pearson (1991) conducted a qualitative study to explore the effects of
disability on the family, specifically the impact it had on siblings. He found that the presence of a
physical disability could affect the dynamics between siblings. In particular, the findings suggest
that siblings share some of the same emotions as their parents, such as anger or guilt towards the
disability. The study also shows that it is common for able-bodied siblings to be jealous of the

attention their brother or sister receives from their parents. Cuzzocrea, Larcan, Costa & Gazzano, (2014) also found that siblings of children with disabilities experience a higher stress level within their family dynamics than do siblings of nondisabled peers and can struggle to receive adequate attention within the family unit. Often, a child with a disability requires more of the parents' attention to attend to everyday needs; therefore, the other children feel left out or less important. Disabled children's families play an instrumental role in helping to shape their attitudes toward independence. Families can unintentionally hinder the children's abilities to mature socially by not providing opportunities for growth and psychosocial development. Having a family member with a disability can affect an entire family in both positive and negative ways. As a result, further studies are necessary to explore family stress related to disability. Gaining more insight into the parenting experience will inform the research community as to whether parents perceive they are treating their nondisabled children differently than their children with disabilities and the impact this has on their family as a whole.

Jones and Passey (2005) investigated the stress that families—specifically, parents—experience when raising children with developmental disabilities. They examined the parents' stress levels as they pertained to certain child characteristics, resources, parents' perceptions of disability, and coping styles. Their results indicated that parenting strategies and family coping styles were the strongest predictors of stress in the home. The researchers found that when parents use a parenting approach that gave them more control over their child with a disability, they experienced less stress. Thus, it is natural that some families within this population adopt a more controlling parenting style.

Sen (2007) performed a study to determine the difficulties experienced by families with disabled children. He also investigated the role rehabilitation professionals play in adding to or

minimizing these difficulties. The study sample came from one public and two private

rehabilitation centers; participants were children with physical disabilities between the ages of 3

and 18 years, who were registered in these centers. Due to the varying cognitive abilities of the

children as well as the vast age range, their mothers were also included in the study. The

researchers chose a descriptive study design and utilized a "personal information form" they

developed based on information in the literature. They collected data over a six- month period

and analyzed the data using the SPSS software. Support from friends and family was lacking for

more than half the participants. In addition, almost all the participants reported that additional

support from rehabilitation staff would make their day-to-day lives easier to manage. The daily

care for children with disabilities differs from that of a typical child; as such, extra support was

deemed necessary by the participants.

The difficulties faced by these families might help to explain why parents choose to adopt

certain parenting styles. When parents are taking on all of the responsibilities associated with the

care of a child with a disability they make the decisions they feel are necessary for their children

in an effort to make their daily responsibilities more manageable. Although this may be a time-

efficient approach, it may deprive the children of the opportunity to make their own decisions or

to progress developmentally. As Sen (2007) found, "The difficulties (e.g., care, psychological,

social, and economic) experienced by family members during the process of adaptation toward

living with the disabled child can lead to conflict within the family" (p. 4). This, in turn,

inevitably changes how the family functions as a unit as well as how willing the parents are to

allow their child exploration into more autonomous functioning.

Aran and Shalev (2007) published a study that closely examined family dynamics. The

researchers examined the dimensions of parenting a child with a disability. The authors found a

positive correlation between an autonomy-allowing parenting style and the quality of life (QOL)

of the children. The impact of parenting style on psychosocial aspects of QOL was far greater

than the other factors assessed in study. Autonomy-allowing and accepting parenting styles lead

to improved mental health, higher self-esteem, better behavior, and fewer social and emotional

limitations for the children. Parenting style is one of the specific factors shown to implicate the

psychosocial aspects of QOL in children with cerebral palsy. Unlike other studies, the

researchers used the participants' typically developing siblings as the control group. This gave

the researchers a firsthand look at whether children with disabilities were treated differently from

their siblings. They found that, in comparison to their siblings, children with physical disabilities

were more coddled, directed and not given as much responsibility in terms of chores or decision

making.

Hauser and Grych (2013) investigated QOL measures, children's responsibility levels

and social function. They found that family dynamics could change because parents of children

with disabilities are not always mindful of how they respond to cues indicating the child wants

greater independence. In order to develop healthier psychosocial functioning, parents need to

encourage their children to undertake more responsibility and form their own ideas. Litt &

McCormick (2015) expanded on why parents may not instinctively encourage independence. In

their correlational study, the researchers found that parents of children with chronic conditions

and disabilities perceive those children differently, in terms of their understanding of the needs

of the child and their own care burden. The perception of that burden in turn affects family

dynamics, how the family functions and how the child is treated within the household.

The studies discussed above illustrate the importance of helping families develop healthy coping strategies to manage stress so that they may be inclined to grant their children more autonomy and encourage social maturity. This in turn may give children more opportunities to work closely with their parents to gain the skills to exercise objectivity. Doing so will help them achieve a higher QOL, enhance their social abilities and interactions and help ensure they can support themselves financially as they age. The research to date illustrates the importance of educating families to ensure they are acting in the best interests of their children.

Quality of Life and Economic Impact

Research has continuously demonstrated that parents of children with disabilities tend to overprotect them. This parenting style then makes the child dependent on their parents and, ultimately, can lower their quality of life. As such, another area to consider is the financial burden that having children with disabilities places on families. Several studies (Barbarin,1985; Brust and Sapienza,1992; Parish, Pomeranz-Essle & Braddock 2003; Wolke, & Marlow, 2013; Ra, Y. A., & Kim, 2016) have shown that while the economic load that every child brings to his or her family may be very high, the care, treatment, and education of raising a disabled child imposes an even greater burden to the family (Fujiura & Yamaki, 2000). This financial burden may continue unabated as long as independence, behavioral autonomy, and social maturity are not encouraged or achieved.

Barbarin (1985) used a qualitative approach to survey families and found that the demands of caring for a disabled child may result in parents giving up work, reducing overtime or having to refuse promotions. He also found that the child's disability could lead to extra costs, including housing modifications, medical bills and equipment that other families do not need to consider.

Smyth and Robus (1989) conducted a study that supported these findings. Specifically, they determined that two-parent families who had a child with a disability suffered increased financial hardship.

Financial support helps families better cope with the presence of disabilities. Wallander et al. (1989) found that family income was positively associated with the "social functioning" of mothers of children with spina bifida or cerebral palsy. Brust and Sapienza (1992) conducted a qualitative study that detailed the financial burden of parents caring for disabled children. The authors described the ways that available money buffers the effects of stressful behavior in families. They used discriminant analysis to examine the highest costs that were endured by these families and found that the time parents spent caregiving was the costliest predictor of financial distress. Families often do not have the resources or time to bring in more money when caring for a child with a disability.

Families comprise the largest group of caregivers for people with developmental disabilities in the United States. Sixty percent of Americans with disabilities live with their families (Fujiura, 1998). Recent studies (Parish, Pomeranz-Essle & Braddock 2003; Wolke, & Marlow, 2013; Ra, Y. A., & Kim, 2016) have found similar results and have detailed the financial impact the families endure, which is magnified the longer the individual remains dependent on their parents. Parish, Pomeranz-Essley, and Braddock (2003) used a multivariate analysis to show that the vast majority of public financial resources for developmental disabilities is devoted to residential services. Families receive very limited financial support to care for their children with developmental disabilities. Furthermore, Parish, Seltzer, Greenberg, and Floyd (2004) found that Supplemental Security Income payments (SSI), provided to individuals who meet strict income

and disability eligibility criteria, are usually insufficient to cover their expenses. The study also found that the longer children remain dependent, often well past the age of 18, the more the costs increase for family members. Petrou, Johnson, Wolke, and Marlow (2013) conducted a separate study that supports these findings, and adds to the trends in current literature using a qualitative study to illustrate the significantly increased economic costs associated with impairment or disability during childhood. Specifically, disability was associated with an average unadjusted increase of £528 (649.33 US Dollar) in health and social service costs and £3694 (4543.25 US Dollar) in public sector costs (including education costs) throughout the span of their middle childhood. Again, as children age and become adults, if they do not have the skills necessary to support themselves, these costs increase (Petrou, et al., and 2013).

Kwiatkowski et al. (2014) examined the impact of age on overall QOL for persons with disabilities and found that QOL decreased as the individual aged, partly due to not having adequate economic resources to sustain a healthy lifestyle. This lower QOL also relates to not having the same increase in benefits as these individuals age and therefore having to rely more on their families financially and otherwise. Employment rates for individuals with disabilities are significantly lower than those of the typically developing population, which adds an increased burden on increasing QOL as individual ages (Kwiatkowski et al., 2014). Although employment is consistently an underlying goal for rehabilitation professionals, families tend to place less emphasis on independence that would lead to employment, which then leads to less autonomy and more burden on the family (Ra, Y. A., & Kim, 2016). These findings illustrate not only the importance of autonomy but also how developing a sense of autonomy in children with disabilities may help to relieve some of the burden on parents and families, who otherwise are likely to be the main source of economic and additional support.

Discussion

As demonstrated in the synthesis, a substantial amount of research has demonstrated the relationship between parenting styles and social maturity and highlighted many of the factors that can influence the outcome within the family. However, most of the studies discussed in the previous section were correlational studies. While this approach reliably shows a positive relationship between parenting style, behavioral autonomy, and social maturity in children with physical disabilities, it does not allow researchers to uncover the underlying reasons for this phenomenon, nor does it or identify contributing factors or present possible solutions. The goal of the present study is to expand the current literature by using a qualitative approach to address why parents choose to overprotect their children rather than leading them towards autonomy. Elucidating the reason for this correlation may help professionals find ways to encourage parents to allow their children more independence. With this added support, families may be more likely to embrace positive change that help to ensure that their children have opportunities to cultivate their social skills.

The approach will examine the social structures and individual experiences associated with parenting a disabled child. Specifically, the study will seek to answer the 'what', 'how' and 'why' questions related to quality rather than in terms of numbers or statistics. It is hoped that the current study will identify key factors that may inform theory development about how parents make decisions and develop parenting styles that may lead to overprotection of their children with disabilities. In addition, it is hoped that results from this study will lead not only to theory development but theory testing and interventional research in the future.

Sufficient studies show that addressing the dynamics of parenting a child with a disability is challenging for rehabilitation professionals and the families with whom they work. However,

up to this point, researchers have not explored the issues deeply enough to comprehend why

overprotection occurs or how to help change the outcomes. Further exploration into the areas of

parenting and social maturity as to how it affects children with disabilities, will help to enhance

the rehabilitation experience. The findings obtained from the proposed study may allow

rehabilitation professionals to gain knowledge and insight about the ways to best help parents

and their children; in turn, this may help ensure that each child has the opportunities reach his or

her full potential.

CHAPTER 3

METHODS

Design

To collect qualitative data, the investigator will use Narrative Inquiry. Narrative inquiry is the process of gathering stories with the purpose of understanding experience and interpreting meaning within that experience (Clandinin, 2013). This methodology is appropriate because eliciting specific stories and examples from participants will allow the team to gather as much information as possible to address our research questions and ensure we capture the authentic experience of each participant.

The primary investigator collected qualitative data through multiple interviews with parents who have children with disabilities to determine their parenting approaches, how they perceive their child's disability, and how rehabilitation professionals can better support parents and provide the support they need to encourage autonomous functioning. Parents were asked questions about their experience involving parenting a child with a disability, how they perceived their parenting approaches have shifted since their child's diagnosis, what they saw for their child's future and what, if any, further information would have been helpful in adjusting to their child's disability. The number of parents interviewed was determined by sufficient data and saturation (Seidman, 2006); saturation was reached when no new information was presented to the researcher and there was adequate data to answer the three following research questions.

(a) What factors do parents feel influence them in 1) making parenting decisions about their children with disabilities that involve questions about autonomy vs. protection; or 2) the expectations they have for their children?

(b) How do parents perceive that they have modified their childrearing approaches and expectations for their children with disabilities?

(c) How do parents feel they could have been better supported through the process of raising their children with disabilities?

Chapter Sections

This chapter is organized into four primary sections: 1) *Participants*, which will include an an explanation of how participants were selected, sampling procedures, and inclusion and exclusion criteria; 2) *Site description*, which will provide an illustration of the children's clinic where the study is taking place; 3) *Measures*, which will summarize the use of interviews, participant observations and field notes for data collection and recording; and 4) *Procedures*, which will detail procedures used in participant recruitment and consent, data collection and data analysis. The Procedures section will also detail the methods used to ensure validity and reliability of the study. The end of this chapter will discuss limitations of this methodology.

Participants

Participants will be parents and children attending the Children's Clinic of Southern Arizona. The clinic serves children all over southern Arizona for both general pediatric care as well as children with disabilities.

Inclusion and Exclusion Criteria

Parents included were those of children whose disability is primarily physical, meaning any disability or chronic disease that left the child with a physical impairment (e.g. not being able to walk, trouble with moments, seizure disorders) that are willing to participate. The age range of the children included children and adolescents (7-18 years) . In addition, all participants had to be English speaking as the PI conducted all research activities exclusively in English. The

wide variety of patients at the clinic provided an opportunity to observe this issue from all

angles. As stated by Stake "The researcher should have a connoisseur's appetite for the best

persons, places and occasions best usually means those who help us understand the case typical

or not" (Stake, 1995). Thus, the inclusion criteria insure the parents interviewed provide the most

relevant information. Hence, the researchers chose not to include parental demographic

information so as not to predetermine what was important information within the study.

Sampling

For purposes of this study, the sampling methods will be a mix between convenience and

non-probability sampling. Non-probability sampling as Merriam describes it is most appropriate,

as generalizability is not a goal of qualitative research. It is purposeful because the investigator

seeks to understand a given population, and involves using a criterion-based selection to create a

list of attributes essential to the study and find a unit matching the list (Merriam, 2009). With this

in mind, selected families will be those that the investigator feel will best answer the research

questions posed in this proposal using the following inclusion and exclusion criteria.

Sample Size

There are several factors to consider when determining sample size, including the

purpose of the study, feasibility, the goals of the researcher and the amount of data that will be

useful with the overall goal of achieving saturation (Seidman, 2006). With this in mind, a

specific sample size was not established prior to the start of the study. The researcher determined

when there was sufficient data as to reach the point of redundancy whereby no new information

is being gained during interviews.

Site Description

This study took place at the Children's Clinics of Southern Arizona. This clinic consists

of 25 medical and dental specialty clinics, primary care and therapy services in the same physical

location. It is a non-profit organization providing family-centered, comprehensive outpatient

medical and therapy services in a comfortable and engaging atmosphere. Children's Clinics is

accessible to the entire community, and serves children from birth through age 21.

In addition to general pediatrics, many of the children served at the Clinic have complex

medical conditions such as cerebral palsy, spina bifida, muscular dystrophy, cardiac conditions,

cleft lip and palate, sickle cell, and metabolic disorders. A large number of staff and care

providers are bilingual in English and Spanish, and translation services are available for all

languages. The clinic has certification through the joint commission, which assures a strong

focus on safety and quality for their patients, physicians and staff. In the past year, the clinic had

22 755 patient visits, employed 69 staff members and 54 physicians held clinics on-site.

<div align="center">

Measures

</div>

For the first part of this study, the researchers collected data from interviews and field

notes. As Merriam (2009) notes, "Unlike experimental, survey, or historical research, case study

does not claim any particular methods for data collection or data analysis. Any and all methods

of gathering data from testing to interviewing can be used in a case study although certain

techniques are used more than others" (p. 41).

Interviews

The researcher conducted a semi-structured interview to examine the feelings, thought

processes, challenges and overall life experience surrounding parenting a child who has a

physical disability. Parents were asked a series of guiding, open-ended questions (provided in

appendix A) to help provide an in-depth account of their experiences. The questions helped

ascertain how parents view their child and treat him or her as compared to their other children, if

applicable. The interview also included questions related to parents' feelings about certain

situations, and ask them to recall difficult decisions they have had to make, the thought process

behind those decisions as well as the feelings, positive or negative, that influenced those

decisions. The personal nature of these questions allowed the researcher to explore each

individual's experience in an effort to gain as much information as possible and be open to any

previously unidentified constructs or factors in order to inform the research questions

sufficiently. The interview protocol for this study emerged via analysis of literature to determine

which important factors to address. Upon completion of pilot interviews, researchers omitted

some questions and reworked others to elicit more insightful responses. After revisions, there are

ten main questions, in addition to some probing questions to elicit further information.

Field Notes

The PI used both descriptive and analytical field notes to help expand upon what each

investigator has observed. These field notes portrayed the context in which the more focused

observations took place. These analytic notes will allowed the team to reflect on observations and

record any ideas or impressions taken during interviews. As noted by Glesne (2011), "it is a time

to write down feelings, work out problems, jot down ideas and impressions, speculate about what

is going on and make short and long term plans for days to come" (p. 76).

NVivo software. In order to organize and analyze the information gathered, the researchers used

NVivo software to visualize findings and justify the decisions made. NVivo research software is

a frequently employed tool used to arrange the unstructured information for qualitative research.

Useful for the classification, sorting and organizing of information, NVivo software provides a means to glean insights that will allow the formulation of valuable conclusions at the end of the study.

Procedures

Recruitment Process

Participants were parents recruited from the Children's Clinic of Southern Arizona. A recruitment advertisement was emailed to the staff at the clinic and was distributed in-person to potential participants. The advertisement contained information regarding the study and provided the contact information for the Principal Investigator (PI). Professionals at the clinic participated by providing relevant information regarding clinic procedures and they selected participants and families they felt were appropriate to answer the research questions. If too few participants responded, a second recruitment advertisement was emailed 3-4 weeks later.

Informed Consent

Prior to the interview, participants were provided with a copy of the informed consent form by the PI at the clinic, unless another location was agreed upon. The PI was the only person answering study-related questions from consenting subjects. The consent form also informed each participant that they could withdraw from the study at any time. Consent for observed families included making a general announcement at the beginning of each observation session and giving families who no longer wish participate the opportunity to let the PI know.

Interview Procedure

One or both parents from each family were invited to participate in interviews with the researcher, depending upon willingness and availability. Interviews lasted approximately one

hour and took place at the clinic or an alternate agreed-upon location. The interview protocol for

this study was created based on analysis of existing literature and data obtained during pilot

observations. The questions focused on asking parents about their experiences in having a child

with a disability. The questions also examined how the parents view their child and treat them, as

compared to their other children, if applicable. Based on pilot information, the interview

questions were revised several times in order to settle on the final questions.

Interviews were transcribed within one week of being conducted and audio files were

deleted immediately thereafter. The researcher assigned each participant a pseudonym within

the transcript and deleted any identifiable information to protect confidentiality. Once all

interviews were conducted and transcribed, the PI and an auditor analyzed content using NVivo.

NVivo is a qualitative data analysis (QDA) computer software package designed to assist

qualitative researchers with large volumes of data and provide deep levels of analysis. NVivo is

used by academic, government, health and commercial researchers across a wide range of fields,

including social sciences, such as anthropology, psychology, and communication, as well as

forensics, tourism, criminology and marketing.

NVivo software allows users to classify, sort and arrange information, examine

relationships within the data, and combine analysis with linking, shaping, searching and

modeling. The analyst can test theories, identify trends and cross-examine information in a

multitude of ways using the NVivo search engine and query functions. NVivo accommodates a

wide range of research methods, including network and organizational analysis, action or

evidence-based research, discourse analysis, grounded theory, conversation analysis,

ethnography, literature reviews and mixed methods research.

Validity

The investigator sought to ensure credibility of the proposed study by using the validation strategies of researcher reflexivity as well as respondent validation and member checks. The researcher provided thick rich description by giving a detailed description of each of the participant and ensuring that interviewees will have the opportunity to review all transcripts for accuracy. Further, The researcher obtained rich data containing multiple examples of each theme by interviewing participants individually and transcribing verbatim.

Reliability

Reliability was ensured by taking care not to misinterpret or misrepresent data and to carefully perform data recording and analysis. The investigator continuously reflected upon her actions and carefully outline all procedures that lead to the research findings. Fieldwork was carried out consistently and interpretations will be continuously checked. All informants had multiple opportunities to discuss their experiences. Throughout the process of data analysis, the researcher recorded her thoughts using memos. Memos were used to note ideas throughout the coding process, as well as in an effort to monitor any personal biases and ensure neutrality on the part of the investigator. Memos also helped to track the thought processes behind any emerging themes. In addition, an auditor reviewed all coding and analysis to ensure consistency and help control for any biases. Finally, all evidence was systematically analyzed using the appropriate techniques.

Trustworthiness

Field observations were made over a four-month period, which will ensure long-term involvement and build more trust and openness among the researcher and participants. In addition, there was an appropriate amount of evidence and comparisons among data sources to

validate finding. Further, detailed descriptions of context and phenomena were written in order to allow others to assess the transferability of the findings and to provide accounts of settings that may be illuminating as extreme or typical cases.

Collection

The process of interviewing, collecting field notes and observations was to collect and analyze the data from the interviews with each of the parents who agreed to participate in the study. Participants were also be given the opportunity to help ensure their identity is protected by changing identifiable information and being instructed to tell the interviewer to turn the tape recorder off if he or she wants to discuss anything off the record.

Data Analysis

Researchers transcribed all interviews and observation notes for further analysis. Data was analyzed using what Merriam (2009) describes as a "constant comparative method whereby the researcher constantly compares within the study the data being collected, comparisons are constantly made within and between levels of conceptualization until a theory can be formulated" (p. 200). In this way, analysis and coding of the data will produce higher-level themes, concepts, and assertions. This process begins with reasonable codes, categories, and themes suggested by the first instance of narrative text or other observations. In coding the data, researchers followed a grounded approach (Corbin and Strauss, 2007). According to Maxwell (2013), "...analysis begins with the identification of units or segments of data that seem important or meaningful in some way… this identification can be based on your prior ideas of what is important or on an inductive attempt to capture new insights" (p. 107). The researcher explored the data openly with no preconceived notions or ideas of what would be found, in order to most effectively extract the elements of the families' experiences with disability that are

important or meaningful.

After the investigator developed themes (e.g., instances of these individuals showing autonomy, the type of environment their parents or family created, the support children receive and whether or not that support was a help or hindrance), the researcher clustered similar topics and generated codes. By grouping several codes together, the researchers gained a full picture of each families' experience with disability and how these experiences affect how the children are treated as well as their overall development. The researcher was also able to detail parental approaches that worked well, what obstacles the families faced, and in which areas families need more support.

Periodic review of the collected data, as well as summaries, helped identify trends in the data that warranted further analysis. Examples of trends could include common barriers the families faced, the parents' views on disability, and how the parents cared for their children. If, as they coded each interview, the researchers identified new concepts or categories that they deemed important to address, they went back and recoded other interviews accordingly.

Using procedures outlined by Saldania (2013), data was both coded and recoded. Cycling back through the first codes allowed the team to identify additional qualitative analytic methods (p. 187). The researchers constantly compared emerging trends, but did so within a tentative structure and incorporating new information until a scheme for classifying and understanding the meaning of data became coherent. These additional categories, along with the use of analytic memos, allowed researchers to create higher-level themes and concepts that related to overall parental attitudes and beliefs that were affecting their child's ability to successfully transition towards living independently. Once we identified key factors that appeared to be influencing those

attitudes (e.g. education, fear, lack of knowledge, preconceived notions of disability, or guilt) we

used that information to develop a theory explaining the different factors associated with setting

expectations in making decisions concerning parenting a child with a disability.

Limitations of the Study

One notable limitation in this study relates to the use of a convenience sample. The

researcher only collected data from parents whose children were enrolled at one site and

therefore may not be representative of the general population based on gender or ethnicity. Thus,

transferability of study findings may be limited. Study bias of the researchers may also present a

limitation; however, all possible precautions were taken to ensure data remains subjective. Any

limitations due to perceived lack of experience was mitigated by the supervision of highly

experienced researchers who helped to guide the practices outlined here.

CHAPTER 4

RESULTS

In response to interview questions, the researchers identified a number of themes and subthemes relating to each research question following data analysis. The themes, along with data to illustrate each theme, are reported below. This section will describe the sample and report findings for each research question individually. Table 1 on the following page details characteristics of the children whose parents agreed to participate in the study, including parental role, the child's age, child's gender, child's diagnosis and whether or not there were any other siblings in the household. Table 2 outlines the themes generated from participant experiences.

Table 1

Participant Characteristics

Parental Role	Childs Age	Childs Gender	Childs Diagnosis	Siblings
Mother	17	Female	Spina Bifida	No
Mother	11	Male	Friedrick's Ataxia	Yes
Grandmother	17	Female	Dwarfism	Yes
Mother	7	Male	Spina Bifida	Yes
Mother	13	Female	Spina Bifida	Yes
Mother	17	Male	Spina Bifida	Yes
Mother	18	Male	Cerebral Palsy	Yes
Mother	18	Female	Cerebral Palsy	Yes

Research Question	Theme	Sub Theme
	1a. Desire to Protect and keep safe	
	1b. Influence of medical professionals nd personal experience.	1bi Medical Advice and Communication 1bii. Emotions evoked by experiences surrounding the child's disability. 1biii. Additional concerns brought on by medical diagnosis-
	1c. Hope	
	1d. Factors not connected to medical experience or diagnosis that contribute to parental attitudes	
2. How do parents perceive that they have modified their childrearing approaches and expectations for their children with disabilities?	2a. Developmental milestones 2b. Struggle with when to push when to assist when to let child try independently and child involvement in decision making	
3. How do parents feel they could have been better supported through the process of raising their children with disabilities?	3a. Parent recommendations for other parents	3ai. Mentors 3aii. Advocacy 3aiii. Emotional Support

Table 2: Themes generated by participant experiences

Research Question 1. What factors do parents feel influence them in 1) making parenting decisions about their children with disabilities that involve questions about autonomy vs. protection; or 2) the expectations they have for their children?

Desire to Protect: A Parents Desire to Protect Their Child and Keep Them Safe

A common theme throughout every interview was all parents' worry that their child's disability would have negative consequences in the child's everyday social life and interactions. These concerns led them to protect the child more than a typically developing child out of concern for their safety and a desire to shelter the children from pain or scrutiny. Parents expressed several fears that contributed to feeling this way and created a greater sense of responsibility to protect their child and how those concerns manifested in every day interactions and reactions in their own lives.

For example, several parents discussed concerns about bullying in public and in school directly related to their child's disability. One of the parents, referred to as OR, fears other children bully her son because he can be hard to comprehend: **"Right now my biggest worry is bullying because there are a lot of people who make fun of him and don't understand him."** Another parent shares these concerns but is hopeful that, as her son ages and his peers mature, the situation could improve and he will have more friends. **"They make fun of my son. I know he wants to go to college…and at this point and my hope is that if he does get involved in a college that the bullying will stop. It seems that they are more understanding of individuals with disabilities."**

In addition to bullying, parents in this study expressed concerns about how the public reacts to disability in general, wanting to shelter their children from negative reactions in the

public sphere. Parents expressed concern about children not being treated or viewed like their

peers. Society has many different views of disability and parents expressed that reactions can be

frustrating and they want to help their children through those experiences.

For instance, one parent referred to as KD, feels that people treat her son differently

because of his disability. She said **"One of the biggest things, when we're out socially, is he**

does absorb a lot of attention from people…they stop us when we're walking and try to

pray for him. It's just a lot of unnecessary attention that I know is coming from a place of

love, but it's very difficult because he is not being treated equally." Parents feel often times

people are unsure as to how to react to their children, so there results a need to be there to

oversee interactions. As DF said, **"Some people don't know what to say or do. I think they**

are just afraid. A lot of people don't know how to approach my son. You know, they stare

or they look at him - they don't feel comfortable enough to go up to him."

As part of protecting their children, parents expressed that they do not let their children

be alone or do things independently. The parents ensure there is always someone there to assist

him or her physically or in social situations to ensure the child safety. There is a constant desire

to keep them safe, which in turn affects how parents treat them. Several parents admitted to

being more protective of a child with a disability because such a disability affected their ability

to handle a lot of things on their own. As one parent expressed **"I want to protect him, as a**

parent, that's what any parent wants for their child, especially when their child has a

disability, because they are very gullible. I don't know if that's the right word. They're easy

prey because they want to be very understanding and very giving, and people use them for

that." In general, parents feel their children with disabilities are more susceptible to harm, and

that such children do not have the tools necessary to protect themselves. They need constant

monitoring and looking after because their social skills oftentimes are not up to par with those of

their peers. Parent DF feels these characteristics have created somewhat of a cycle for her

daughter. She sees her daughter as more gullible and less socially aware but also says that she

probably became that way from being protected constantly and never being left alone to adapt to

situations herself. The following transcript from an interview demonstrates her thoughts:

**DF: "…there are adults with her that are looking out for her. We don't leave her with
caregivers that we do not know. We have to totally trust them before they're left with her. I
have a fear of her getting hurt and she's very gullible, and she knows that. She knows that
she's gullible. And she's easily swayed by people that she believes their stories, and can be
taken in and she knows that. So, we're careful…"**

Interviewer: why do you think that is?

**DF "Because I think she's been so protected, she's always had adults around her. She's
never been exposed to the lies that people will tell to get their way. She's never really
learned to be savvy."**

<u>Doctors' Influence: Medical Professionals and Personal Experience Have Influence</u>

Several parents discussed the influence of the information given by medical professionals as well

as the experiences the parents themselves have had surrounding their child's diagnosis. These

factors all have an impact on parental attitudes toward disability and, in turn, how they make

decisions concerning their children.

Subtheme: Medical Advice and Communication

The parents who this study interviewed have regular interactions with medical professionals; the

interviews made it clear, through their responses to several questions, that information that comes

directly from the doctor has significant influence over a parent's behavior or actions toward their children. Every disability has different experiences attached to it, and each doctor handles conditions somewhat differently. Nevertheless, the interviewees exhibited some similarities and influences to consider when receiving the prognosis of a disability before their child was born. In most cases, parents expressed high levels of fear because the doctors or nurses did not provide adequate information. It was up to the parents themselves to draw their own conclusions, and in many cases, do their own research.

One parent, referred to here as BC, recalls being very afraid because, after getting very little information from her doctor, she attempted to fill in some of the gaps on her own. Her research – and lack of expertise – led to her becoming inundated with frightening information that was not necessarily accurate. She noted **"Reading on the internet is really scary. That was not the best route to go. By the time I got to the specialist, I had already figured out that she would be born with spina bifida. I just was more wanting to know what that would mean for her because the internet scared the heck out of me. I was not sure what that meant."**

While in some cases the parents agreed the doctor gave more information, in certain cases even that backfired in a way because they were given the worst case scenarios. Doctors told many parents to expect the worst. Some were told to expect a very low quality of life. Additionally, doctors told some parents to prepare themselves to say goodbye to their new child. This instilled a great deal of fear in parents and set up an expectation that their child was not going to have a typical upbringing, or in some cases going to survive at all. When EW's doctors realized her son had a disability, she was told not to expect a "typical" child from day one. She illustrated this: **"I was told not to expect much. It was sad. They said he wouldn't have a normal life, he wouldn't walk, or talk."** BC recalls a similar experience**, "The specialist kind of laid it on**

rough. He was like she'll never walk. She might have a mental disability. Most likely, your marriage will be ruined because it's harder to raise a kid with a disability." For these parents, setting lower expectations for their child started before they even had a full understanding of what he or she would be capable of doing.

Along with presenting parents with a diagnosis, some doctors discussed terminating the pregnancy as an option because of the hardships that lie ahead, assuming the parents were incapable or unwilling to raise a child with a disability. Three of the parents interviewed recalled experiences in which doctors not only presented termination as an option but also why it may be a wise choice.

BC recalled the conversation with her doctor, "he asked do you want to terminate? We were like no, that's not even an option. We were given the option to terminate, he was pretty negative. Once I told him pretty firmly that, no, that wasn't a choice for us, he was a little more supportive. Even things like he wanted me to get an amniocentesis and he wanted to see if she had any other genetic abnormalities, he called them."

One of the other parents, SP described how her doctor discussed termination once he realized there was going to be an abnormality with the pregnancy: **"The doctor kind of mentioned something about that there were always alternatives for my daughter, if she wished to pursue them since the baby was going to have something wrong with her at birth."** In both instances, these parents were warned multiple times about the difficulties they would face, as well as medically advised not to have high expectations.

Throughout the interviews, many parents expressed frustration over the information medical professionals had provided for them. They felt either that they were not given enough or accurate information to best support their child. Many parents wished that the doctors had been more

optimistic and given them hope throughout the process of receiving a diagnosis. One parent said **"I just wish that she would have been a little more optimistic and given me a little more hope and not such a limited view. Just hope, that's all I needed."** Parents generally wanted to feel more supported by their doctors. In addition to support, some felt that medical professionals should have been more responsible in providing them with resources that could help them prepare for this alternative parenting experience that provided its own set of difficulties. Some examples of this are as follows.

> **OR: "There are resources out there but nobody knows where to go to because schools and other agencies don't want to tell you because they don't want to risk having to share money or they don't want to have to search for things—they don't want to get off their butts. It's frustrating because they don't want to have to do the work. I wish I knew better."**

In addition, parents expressed that most of the information doctors and professionals provided them was medical as opposed to practical. Doctors did not help support the parents in terms of information that would help in day-to-day life or discuss things parents should be considering. Their chief concern was always medical. In turn, parents were given no guidance on approaches to allowing more independence or what to consider when forming expectations for the child throughout the development process.

AP remembers feeling overwhelmed and wishing she had more to go off after talking to her doctors**: "Pretty much they just give you basics- and then there's books that I got and started reading, kind of to know what exactly CP was and knowing how it affects the muscles and things like that. It was up to me to figure out how that information applied to my son."** BC had a similar experience in talking to the doctors: **"…you got this very medical viewpoint, but nothing about my kid as a person."**

Sub Theme: Emotional Impact: Emotions Evoked by Experiences Surrounding the Child's Disability

The medical aspect of the disability evokes many emotions in parents that are often difficult to deal with. Often to cope with the feeling of a lack of control, parents take on added responsibilities to attempt to exert control, in this way impacting the attitudes they have towards their children. In this study's source interviews, parents discussed how they are responsible for tending to their children's emotional needs surrounding medical issues. Parents feel an added sense of responsibility to support their children specifically because of their disabilities. They feel there is an additional level of need from their children because the associated medical issues are very complex and frightening. Parents feel that by having more of a presence they can "provide more of an explanation and ease fears."

Parents go through many emotions after a child is born with a disability, and the diagnosis significantly affects their view of the future. In discussing this throughout the interview process, parents reflected on how their parenting approach shifted. For example, OR spoke about how she felt when her son was diagnosed**: "When I first learned, it hurt. I felt like I had let him down but I had to put that in the back burner because the only way that he can succeed is if I am strong for him. However, the diagnosis felt horrible cause you want the best for your child."** Several parents shared similar feelings of guilt and that sense of loss because the disability was unexpected. DF illustrated further: **"You just think that they're going to be healthy. That they're going to be ok; everything's going to go well. And you hope for that. But you don't really think that this is going to happen. I didn't…"**

There is also the added emotional burden that comes with medical uncertainty, and some parents do not provide the freedom for their children to address indecision on their own because of

the added emotional stress associated with making those decisions or the possibility of making the wrong choice. As DF explained, **"The emotional part, I think is a little harder when you see the hurt. I just try to help her deal with it. Try to help the best way I knew how to make her feel that it was going to be okay."** Several parents expressed that they had felt overwhelmed by the amount of information they were flooded with in the beginning of their disabled child's life. Moreover, the idea they could not handle everything the child was going to need was itself overwhelming. As such, their parenting approach was more hands-on from the beginning because the level of responsibility extended to so many additional areas. *As TG said:*

> **My biggest fear was probably not being able to fulfill everything, I mean all her needs. Or getting all the, especially the medical attention that she needed. She was fragile. It was so scary because I thought how am I going to go home, or wherever I was going with her. I was afraid. Because you see her in the hospital she has all these tubes, the IV, and everybody's seen her. Very overwhelming.**

Adding to feelings of being overwhelmed, the experience of having a child with a disability and starting that journey was very traumatic for some of the parents this study interviewed. In most cases, doctors considered the child medically at risk postpartum, adding not only to the level of stress parents were experiencing but also reinforcing the notion that it was the obligation of the parents to constantly monitor their child from day one. As a result, parents chose to take on more responsibility one parent, referred to here as AP recalls her traumatic experience the day her son was born. AP: **"I almost lost him at 16 weeks, so they stitched my cervix and I was on bed rest, and they still came early. He was actually born not breathing, so they had to resuscitate him, and it took some work to get him back to breathing, so before then, I really didn't know, but once they were born, I didn't leave their side."**

Another parent also spoke about how worried she was once her daughter was born and how the traumatic experience largely shaped her interactions with her daughter. TA: **"…she was born in DC so I left the hospital without my baby, because she was transported here like four hours after she was born. I had to give my permission over the phone to a doctor to perform a surgery. I mean can you imagine, they're asking me 'do you give me your permission to perform a surgery' and I'm not with her. Like, I'm never leaving her again. It was a shocking thing."** The severity of these experiences had a lasting impact on many parents, indeed shaping the decisions they have continued to make concerning their child moving forward.

Sub Theme: Additional Concerns: Additional Concerns Brought on by Medical Diagnosis

Along with the quite common rollercoaster of emotions, parents identified many concerns affecting their own attitudes towards disability, and in turn, their approaches to childrearing. In several interviews, parents expressed fear associated with the implications that came with physical disability. For instance, many parents are intimidated by the prospect of their child lacking the physical access to day-to-day activities and the equipment they need to thrive. They have the attitude that, from the beginning, they had to oversee and be responsible for such factors.

The responsibility fell on them to ensure that their child could overcome many physical barriers and fully function daily. KD recalls the struggle she had with access as her son grew older with regards to the added responsibility she shouldered as a result**: "Just finding a new home, making sure that it's adaptable or modifiable over the years is such a struggle but he doesn't consider all of that; I do."** Several parents also expressed physical access beyond architectural barriers. For some, they worry most about their child not being able to physically

access activities or fully take part in social situations. These barriers cause parents to involve

themselves more simply to find a solution to ensure their son or daughter is never excluded or

held back from pursuing a goal or dream. BC has significant experience with this, given that

several of her children have disabilities. She never wants them to feel left out or shortchanged, so

she has become intensely involved to act as her children's advocate for access and participation.

"I want things that add to their life…. I work on getting resources for the stuff

…were good on the doctors and stuff but the other stuff, the just kids' stuff. The day to day

living. I have to do more like they want to ride a bike. OK, how do I get them a fast bike?

They want to take dance, how do I do that? They want to do gymnastics, where do I go,

that kind of stuff that just lets them be kids. There's a lot less, I find it's really hard and it

just takes hours and hours and hours, which is OK, but it falls on me because I don't know

who to go to, to ask that kind of stuff to."

Along with making sure their children have access comes a responsibility to ensure

children have the tools to meet the physical needs brought on by their disability. Due to their

physical diagnosis, several of the children discussed in this study's interviews had physical needs

requiring more assistance than most non-disabled children their age. Once again, in most of these

cases this added responsibility fell to parents or guardians. SP says that her granddaughter's

physical needs require her to be a constant presence in her day-to-day life. She describes this

further: **"Well, I need to be right there when she got home from school or when she woke up**

in the morning to help her get dressed. Halley is unable to dress herself independently. She

does not have a lot of – what are they called? Daily living skills – that she can leverage to

complete tasks on her own, so she needs me." In the cases of several families, they recognize

that the assistance they are providing is more invasive, but when dealing with medical concerns in particular it is difficult to know when to encourage independence and when to assist.

For example, KD is aware that her son is old enough to handle toileting needs on his own; however, because they are a physical challenge, she helps him to ensure they are done correctly and do not lead to complications. She expands further: **"That's something he's going to have to eventually do and I pushed it a lot for me to do it or for him to have assistance with his teachers or his aides doing it. He is just not open to it right now, and it's hard for him."** TW also noted how she blames herself for her daughter being less self-sufficient in these areas, as she hoped she would be by now, but those decisions came back to not wanting to see her daughter struggle. **"I was helping her with getting up in the morning. There was like a half hour in the morning. It is faster for us to help them. So I blame myself, because she was used to me doing that for her, so it was faster. So things like that. I mean at the beginning it was harder for me. For her it was, oh my gosh, tremendous…. so we have to take that step to do that. I don't want to watch her struggle."**

In addition to physical access and needs, physical health and well-being were likewise major objects of several study participants, but particularly in their decisions to pursue surgeries. In some cases, those surgeries led to lengthy hospitalizations and added medical complications for the children involved. This resulted in them requiring constant care from their parents. In addition to the constant physical care, there was of course the emotional toll of constant medical procedures and worry. Parents shared how they made efforts to shield their children from additional fear or harm during these times. OR described just such a circumstance: **"…he [my child] has had 60 procedures. I protect him; him and hospitals – they're not friends. So, he and hospitals – he'd rather not have to be involved with them. He gets squeamish."**

Moreover, when dealing with congenital disabilities, these types of concerns are ongoing. Accordingly, parents constantly face the struggle of feeling the need to offer more assistance while simultaneously attempting to find a balance to allow for more autonomous functioning.

Hope

Throughout the interview process, parents expressed the desire for their children to live a full life. Often, when asked to elaborate, parents illustrated that a full life consisted of the child becoming more independent and less reliant on his or her guardians. Each parent indicated a hope that their child would continue to progress and find their independence as they developed. Despite such hope as a guiding force and general optimism among parents, children did not always actively engage in becoming more independent. Parents believed there were other factors that would help their child become more self-sufficient without having to work continuously towards that overall goal.

Several interviews concretely illustrated a disconnect between parents' desires for children's independence, and behaviors that foster independence themselves. Many parents expressed hopes and desires for their children to be independent, less reliant, live on their own, find jobs, go to school, etc. Those expressed desires did not always translate in ways that would indeed foster such independence because, in those same families, the children relied heavily on their parents. **When DF was being interviewed, several of her responses contained her desire for her daughter to find independence one day, but at the same time she acknowledged she would never leave her daughter alone for fear that something would happen to her. She also told the interviewer on several occasions that her daughter was "gullible" and "has never been exposed"** to difficult situations. Those same situations, for most teenagers, help foster a sense of autonomy and self-reliance.

In most cases where parents expressed a desire for their child to have more independence, they also acknowledged that he or she was not at that point in their lives. For instance, AP acknowledged that her son, now 18 years old, could be living independently; while she wants that for him, she feels he still has a lot more to learn before he would be able to do so successfully. She illustrates this more fully: **"Well, I wouldn't want him to be anywhere else. He has a good home; he has his own room, his own bathroom. He just lives in our house, and I felt like if I kept him at home and was able to continue to give him the care that he needed, that that would benefit him in the long run."** She maintains a paradox in that she says such things, but at the same time referred to her desire to see him independent someday. SP purveyed a similar outlook, whereby she encourages her granddaughter to pursue her dreams and be independent but at the same time declares**, "She still relies on me for a lot of things, and between me and my husband we help her with most of her daily living."**

Many parents also found hope in their religions and held beliefs that a higher power would not only protect their child but also guide them to a better place in life. For some, they felt as though the support they gave or did not give the child was not going to dictate the child's level of independence – that independence was up to God. In essence, the children of these parents had their fates already decided. As DF explains:

"Her being more and more independent. We have a hope. We believe that, and in the Bible, that it talks about a time when sickness and death and pain and all that stuff will be no more through God's kingdom. And so, we do believe that there's going to be a time when she'll get out of the wheelchair. She'll be healed and live an easier life.. That's what the Bible promises."

Several other parents share her belief that if it is God's will for their child to be independent, it will happen. This belief helps them to feel they can place their child's future in the hands of God, thereby decreasing their own share of responsibility to behave in ways that promote independence. Several parents expressed that having that level of faith was extremely helpful in allowing them to feel less overwhelmed by their child's disability. Many parents expressed that being able to put their faith in God was a lifesaver in many ways. TG feels God is going to help her daughter thrive and, as a parent, she is carrying out His wishes: **"As a Christian person, it's just a matter of understanding more and just being willing to help. It's just you have to do what you have to do, and you have to learn a lot of things, and help in every way possible."** She says that, even in moments of despair within her family, their faith sees them through.

For several families, though the idea of independence was ideal, the process of their child achieving it seemed daunting. Many had the hope for it in some vague future, but few seemed able to fully accept the personal accountability to see it through or make the process more manageable for their children. Several parents relied on external services to promote their child's independence. In their own minds, they had given their child all the resources they could, with the hope that those services would foster independence. Parents felt they had "done their job" in giving their dependents everything they needed – including services that alone would be enough to make children be independent and flourish. As TW noted **"when she was younger I did everything the doctors told me to, she has been receiving all of the services we were supposed to sign up for in order to help her move forward."**

Most of the interviewees talked about independence as a future goal but did not express concrete plans for reaching that goal. When asked where they saw their child or their hopes for the future, what was most important was that their child was happy.. That was their biggest hope,

even if happy did not necessarily mean independent or self-sufficient. As OR said, **"Whatever he is doing, enjoying himself. I just want to see him enjoying himself. If he's not married, he might have an aide, but whatever he's doing, I just want to see him enjoying life." TW and DF both declared they would take it one day at a time, and as long as their child was happy, everything else would fall into place.**

External Factors: Factors Not Connected to Medical Experience or Diagnosis That Contribute to Parental Attitudes:

According to the interviews this study gathered, while the diagnosis and medical community has an immense impact on parental decisions and attitudes, other identifiable factors outside the medical realm influenced how parents treated their children.

For some of the parents, having previous experience with disabilities, such as with a family member, friend or individuals in their work environment affected how they viewed parenting a child with a disability. Several thought that previous experiences gave them a deeper level of understanding and helped throughout their parenting journey. KD says that having a sister with a disability helped her and her son immensely during his upbringing: **"I'm fairly lucky. My sister, she had severe autism and growing up with her, she's 15 years younger than me so I kind of had an eye-opening experience of the world. My stepmom kind of filled that role as an advocate before I became a parent."** AP had a similar experience with a cousin: **"…he was severely disabled and I took care of him a lot".** For these two parents, those experiences provided perspective that acted as a useful tool in their own activities raising children with disabilities.

In contrast, for the interviewees who had no previous experience with disability, the lack of understanding of disabilities had an impact on how they felt once their child received a

diagnosis. DF found, **"I had a very narrow view of people with disabilities. I didn't think capability was very high for anything because there was really no exposure."** OR had a similar experience, noting, **"Before, I really didn't understand disability. I knew that people had disabilities … prior to my son I didn't know the full spectrum of what was needed in their lives."** The lack of exposure could lead to a negative view of disability that influences feelings parents had, once it actually became an integrated part of their lives. EW weighed in on the idea: **"I always knew it was out there, and I think you see it and you see people that have disabilities and you just are like, you feel bad for them, it's so hard, or how different it's going to be until you have a kiddo with a disability."**

Cultural background was also identified as a significant factor for some of the interviewees in how they viewed disability and in turn how they viewed their child. Some parents, like OR, grew up in more accepting cultures and experienced diversity, allowing for a better outlook on disability. OR yielded some evidence of this: **"…perhaps it's because I grew up in a family, a multi-cultural family. My father's African-American, my mother's European. I've never seen lines, [that divide people] if you will."** Others' cultural backgrounds may have made experiencing disability more difficult because their culture was not as progressive or forward thinking. TW saw this first hand when she was growing up in Mexico. **"I see how the houses are built and things like that, and they don't think. Somebody can be, can come here with a wheelchair or steps or, I could go on and on with that and not think about it."** She described how having her daughter was an eye-opening experience and she had to force herself to learn not only how to cope personally, but also how to help her daughter, despite being unfamiliar with the situation herself.

 Research Question 2: How do parents perceive that they have modified their childrearing approaches and expectations for their children with disabilities?

<u>**Developmental Milestones**</u>

When talking about expectations, several interviewees identified different areas where their approaches toward their child with a disability shifted, triggered by their children attaining specific developmental milestones. For example, in some cases their expectations changed over time. Parents expressed that, as their child got older and they had more of an idea as to the challenges their child was facing, parental anticipations shifted. EW says there are considerations she has to entertain for her son that most parents need not think about for their children**: "That plays a part in how much to expect for him, you have to plan for worst case scenarios and kind of have a situation for that, but it's hard to. At the same time, we kind of live this life that anything could happen. It's in the cards for us, whatever it is. We don't expect a lot because things are very unpredictable."** Several parents likewise noted unpredictability as a factor contributing to their inability to set many expectations, citing the fact that they cannot control the unknown.

While parents in this study recognized that their children are not always reaching typical developmental milestones, they noted their expectations shifted in favor of manageability according to their child's individual needs. AP described the nature of this process: **"…it's kind of a day-by-day thing. He [my son] expresses that he wants to do DJ-ing and stuff like that...We haven't really talked about him living independently. We try to give him as much independence at home as we can; we are realistic."** For AP and several other parents, having other children in the home who were siblings highlighted when their child with a disability was achieving typical developmental milestones – or when they were not. Recognition of failure to

achieve the same developmental milestones as their siblings led parents to alter their own

expectations and decisions about parenting.

Some parents said they had the same expectations for all their children, with or without

disabilities, while others admitted they had changed their parenting approach depending on the

child. AP illustrated this: **"The expectations are different. I think her expectations on a lot of**

things, I have higher for her than I do him, just because I know that she can do more things

without assistance than he can. So, I think it is a little ... you know, it's so different with

both kids." OR and SP also admitted to treating their children without disabilities differently

and holding them to higher expectations. SP**: "Raising my children, and my granddaughter**

and my children, and yes, for the other children, for her sister; I expected them to do more

than their sister. She gets very tired. She tires easily. It seems to be it takes a lot of energy

to get up and go to school; and then do her homework, and get ready for bed, and all of

that, and eat."   EW also discussed how she does not expect as much from her son compared to

her other children because he has been through so much that she wants to give him a break and

make living easier.

One of the other important milestones discussed in the interviews was socialization.

Many children of the parents interviewed had not reached appropriate social milestones because

of their parents' reluctance to let them socialize independently. Parents said they had to make

sure their children were okay, noting that there were many more factors to consider in social

outings than with more typical children. As BC said**, "…because you know for a fact, when**

you're taking him somewhere, you're going to have to be there the whole entire time,

making sure that the safety's there." Every parent in this study interviewed expressed some

level of concern around their disabled child's socialization and everything they need to consider

with regard to social activities. While many children grow into independently participating in outings and social events, these parents' added concerns make it so that they feel they need to be present if their child is to remain safe. EW: explains those concerns:

"A lot of additional considerations make it a lot harder. Definitely. We went to Cancun, and it was wonderful, but you have to think in your head, are we going to be able to get a shuttle to the hotel that will fit a wheelchair, how is that going to be through customs, can we take his medication, what happens when we're at the beach, what kind of rooms do they have, are they handicapped accessible. It's just a lot more planning and we need to make sure he's ok"

When discussing typical developmental milestones, the interviewer also asked about dating habits for any children who were in their teens. Specifically, each parent was asked whether mom or dad had discussed dating with their teenager and how and if they approached the conversation. Most parents said either they did not discuss it or that the subject had not come up; indeed, they all avoided answering the question. AP provides an example of this: **"No, not really dating. He went to prom with a girl when he was going to school at ASDB. He has a couple of girls that like him at the day program. He hasn't really gone out on a date, per se, with a girl. He goes out with the guys and has guys' night out and stuff like that, but we haven't really done any of the dating."**

Other parents like OR described their teenagers had not expressed interest in dating yet, so the conversation had so far been absent. When discussing her daughters' dating habits, TW said she had not discouraged dating and had always been open to talking to her daughter. However, TW considered her daughter would have different experiences than most girls her age

owing to her disability: **"She has some idea of dating and I have been, I mean it hasn't happened yet, but yeah I try to guide her, because for her it will be different."**

Assistance vs Independence: Struggle with when to push when to assist when to let child try independently and child involvement in decision making-.

When asked about what parents expected as their child continued to grow, parents had different expectations for the future. They were able to tell me what their expectations for their child were, but there were some discrepancies between whether those desires were realistic and why or why not. For AP, she knew what her son wants to do but also does her part to ensure that his goals are what she considers achievable. **"He wants to be a Vet Tech, he started out wanting to be a doctor, and that started you know, he works in the summers with animals, he volunteers his time and they work with other kids that are disabled."** DF seemed to want to have high expectations for her daughter with the condition that her daughter was more proactive; she said **"I would like for her to progress and be more proactive both in word and in actions, events that would be good for her, and just to help her grow both physically and mentally; but to be proactive."**

Nevertheless, DF is like so many other parents struggling with when to push and when to assist or let children try things on their own and be more active in making decisions about the future. Most parents in this study struggled in this way, and erred on the side of giving more support rather than letting their child figure out a difficult situation on his or her own. This was due at least in part to a lack of surety with regard to when it is appropriate to push them. KD shared that she also has a difficult time making some decisions because she wants her son to develop as typically as possible and reach milestones similar to his peers, but she struggles with wanting to offer more support. She was clear: **"How much do I push? How much should I**

push? Am I making the right decision to not be on him as closely as I was? Those are very

hard choices to make.”

Some parents expressed that they consciously try to offer their child more opportunities

to make decisions and communicate about desires and needs. This fosters and encourages

independence. As SP **said, “Now with her being a teenager I think that we do it together. I**

tell her what I have heard or, what is going on. What I need to kind of respond to? I ask

her what she would like to do, or if she has input. I think we make decisions together now

whereas when she was younger; of course, I made all the decisions.” Still, even with more

decision-making power, most parents in this study were conscious of still being involved in all

major decisions concerning their child.

Research Question 3: How do parents feel they could have been better supported through the

process of raising their children with disabilities?

<u>Parents’ Recommendations for Others</u>

Parents expressed what they would recommend for others in similar situations. In certain

cases, not having appropriate resources influenced their childrearing approaches. For example,

several parents said that if they had mentors to help guide them, they would have made different

parenting decisions. Having other parents who had gone through the same thing to share

resources and offer support, according to the parents interviewed in this study, would have made

a significant difference. Seeing how other parents handle similar situations would have given

these parents an idea as to how they could handle situations. As for their children, it would have

helped them see other individuals with disabilities as common, and may have acted as a

motivating factor and helped them continue to push themselves. KD confirmed this: “Like a

mentor, a peer to peer there to help and give advice.”

Other parents discribed how helpful it would be to have additional resources. Access to parental resources is crucial in both encouraging independence of the children and relieving pressure from parents by helping them not second-guess their decisions or worry as much about when to push versus offer assistance, the idea being that the resources available will better prepare children to be more independent. OR expanded**: "…there were various resources that I should have had. And see, that's the key word. Everything's "should have". … I was told transportation wasn't available when it actually was. And that hinders his independence, too. It did. It really did."** Awareness of supports and different ways to encourage independence was key for several interviewees, and they mentioned promoting such awareness would likewise help many parents going through the same struggles. AP illustrated thusly:

"…well, I guess if they gave classes, I think, to parents, maybe. If the kids are in the NICU for a long period of time, if they offered some kind of classes that they can take that kind of explained a little bit more about now and in the future, what's going to happen. I think that could help you and maybe give you some kind of counseling to prepare you for what's going to be ... the outcome, once the babies leave and you're the one taking care of them. I think that would be helpful."

Some parents said that once they found the ability to advocate for their children, they could push more for their children and fight for them to reach their full potential. EW discussed this: **"I think most every professional normally helps parents and they cover as much information as they can. I think just reaffirming parents that there is the help out there, if they need it, you know. Not to be afraid to ask for it… always be your own advocate."** Some parents found that advocacy was a driving force in their ability to go about ensuring that their child had rights and could become typical contributing members of society.

This nevertheless has its own difficulties. Because it can be exhausting to constantly advocate, parents expressed the importance of finding a balance – not just for themselves, but also for their children.. The importance lies in finding a balance for one's children, given all the "extra things" they need to deal with. BC illustrated this point for the interviewer:

"From a mom, I'm a part of a lot of special needs groups and a common theme is making sure that we create some sort of balance for our kids academically and socially. Just trust your kid. They're going to drive that force for you and they may not be the best student, but they might be the best friend that someone is looking for. That's, I think, the most important advice I can give someone that's starting out in this world."

CHAPTER FIVE

DISCUSSION

The purpose of this study was to gain a better understanding of how and why parents make decisions to overprotect versus allowing autonomy, and gain a clearer understanding of how such decisions affect children long term. The study was designed to examine the lived experiences of families whose children have physical disabilities to provide greater insight into that process and the factors that contribute to parenting decisions. Divulging into first-hand accounts of their experience helped to fill a gap in the literature by applying our qualitative approach to examine the social structures and individual experiences as well as the attitudes and perceptions associated with parenting a child with a disability. This helped to account for some of the intricacies involved in the parenting experience that the literature available to date has not yet explored.

The researcher was able to gain a greater understanding of the families and their children that we in the rehabilitation profession might now apply to deliver more comprehensive, well-rounded and useful services. The data provided a deeper understanding of the dynamics associated with raising children with disabilities.

The results of this study illustrate the myriad of factors parents feel influence them in making parenting decisions about their children and the expectations they have for them. These identified factors were seen to both positively and negatively influence children as they developed. Identification of these considerations also has important implications for professional rehabilitation practice, advocacy and policy reform. Moreover, this study provides an alternative representation of what it is like to parent a child with a disability and includes the medical influences while also going beyond the medical aspect to provide a window into the emotional

and challenges experienced by the families in relation to disability and the influence these emotions have on parenting decisions and expectations.

A previous review of the literature identified a gap; researchers had been able to establish a correlation between parenting style and social maturity and the negative impact it has on children with disabilities. This study, however, identified factors to shed light on the question of *why* parents make parenting choices that overprotect their child and limit their development of autonomous functioning. The results of the present investigation provided insight as to why this correlation exists, aimed at helping professionals find new ways to support parents in allowing their child more autonomy, thereby enhancing the possibility of increased independence.

By isolating the sample to include just children with a physical disability I was able to get a deeper understanding of the implications of an overprotective parenting approach on children, related to social maturity and autonomous functioning that are not necessarily related to disability complications. In addition, I was able to use the data to help inform recommendations on how we in the rehabilitation profession can help families address those complications. Currently, no recommendations exist to address the need of parents and families specifically. This study clearly demonstrates that medical professionals have a significant impact on how parents cope with disability and the decisions that they make. Furthermore, given these findings, it may be helpful to parents if rehabilitation professionals took it upon ourselves to help them with the emotions that come with raising a child who has a disability. Parents may be able to benefit from finding ways to cope and feel supported so they will feel comfortable enough to allow their child opportunities for independence. Specific recommendations for practice and future research opportunities are discussed at the end of this chapter.

Research Question One: What factors do parents feel influence them in 1) making parenting decisions about their children with disabilities that involve questions about autonomy vs. protection; or 2) the expectations they have for their children

Based on the experiences of these participants, protection was one of the main factors that influenced them in making decisions for their child because first and foremost, they wanted them to be safe. The presence of disability seemed to lead parents into presuming from the beginning that their child was not safe and constantly monitoring them was a chief parental responsibility. In doing so, however, they tend to shield their children from any negative consequences related to disability they perceive might occur. As seen in the results chapter, bullying, negative reactions from the public and difficult emotional reactions all contribute to parents wanting to manage their child's experience to protect them from emotional harm. However, as is consistent with current research, we know it is important for all children to take some risks, experience failure and learn from their experiences, to not only succeed, but also understand the importance of consequences (Homebeck et al., 2012). In life, consequences are themselves teachers. Failure to experience these consequences results in children not learning the skills necessary to be independent. In the case of these participants, the constant desire to protect their children is a factor leading to not only how they choose to parent but also how the child develops.

This tendency to avoid consequences speaks to the type of environment created by the child's parents. Previous research has shown that parental attitudes and styles can affect the level of independence children achieve. (Cappelli, McGrath, MacDonald, Katsanis, and Lascelles, 1989). Since we know that parental attitudes are directly correlated with several variables related to independence, it is critical to understand parents' feelings and how to best help them

guide their children toward the independent futures they hope to see achieved. Current literature

shows that these are legitimate concerns because children with disabilities are more susceptible

to victimization behaviors such as bullying and negative social attitudes towards disability.

Schroeder, Cappadocia, Bebko, Pepler, & Weiss (2014) found wide-reaching negative

repercussions of bullying specifically for children with disabilities researchers found that

children with this population are significantly more likely to be victimized by their peers in the

form of both physical and emotional bullying behaviors. In addition, research also suggests that

the majority of bullying and negative attitudes connect directly to specific characteristics related

to the child's disability. (Rose, Monda-Amaya, & Espelage, 2010) While it is likely, given these

findings, that these parental concerns are warranted, provisions need to be put in place to better

support parents and educate both children and parents that the presence of a disability does not

automatically equate to an inability to protect oneself.

We know from existing theory that the environment in which a child grows up is an

essential component in helping them to develop and mature in a social setting. Children need the

opportunity to nourish the maturation process and, in turn, learn to adapt to certain social

situations by acquiring new skills and behaviors. Consequently, it makes sense that present data

shows parents are concerned with their children's level of maturity and ability to handle certain

situations. When looking at the full picture presented by the participants, however, their

parenting strategies are not providing their children the opportunity to nourish those skills due in

large part to their fears, which are not being adequately addressed by rehabilitation professionals.

Given the findings from the current study, it may be helpful to parents to provide access to

rehabilitation counselors who can address some of their fears and discuss how to take calculated

risks while at the same time still supporting the development of necessary decision-making skills

(Fink, Deighton, Humphrey, & Wolpert, 2015). Rehabilitation counselors are uniquely suited to do this because of their unique skill set and scope of practice. They can provide mental health support and family integration with the disability-specific knowledge and skills that other professionals with whom children with disabilities generally come into contact often lack. (Ethridge, Rodgers, & Fabian, 2007).

It is imperative that rehabilitation counselors educate parents on the nature of negative societal reactions and warning signs that may predict their child is being victimized. In addition, it is important to implement a team approach so everyone in the child's life can act as a support. This includes, school personnel, parents, school counselors, administrators, and other student support personnel. Working as a team to support the child ensures that everyone understands the social dynamics that contribute to bullying and negative societal attitudes and how these dynamics can be addressed (Farmer, Farmer, Estell, & Hutchins, 2007)

In addition to being able to recognize victimizing behaviors, it can be helpful for rehabilitation counselors to work with the family as a whole and ensure children themselves have strategies to recognize and deal with victimizing behaviors within society (Ross & Horner, 2014). Strategies including but not limited to teaching and reinforcing productive social-emotional skills and relevant social competency skills to children more susceptible to experiencing bullying or other types of victimization (Meadan & MondaAmaya, 2008). Helping children develop the skills necessary to be prepared in these types of situations may help to ease parental fears and open avenues for increased independence.

Previous research has supported the fact that parents treat children with disabilities differently, causing them to experience postponements in their development. (Homebeck et al. 2002) The current study supported the findings that there was a significant relationship between

parents being overprotective and children with disabilities showing less behavioral autonomy, as parents themselves expressed frustration in this regard .Furthermore, the findings from the current study helped to explain why parents tended to be more overprotective toward their children with a disability compared to their nondisabled children. In addition to wanting to protect their child, medical professionals were seen to have a great influence on how a parent perceived disability and then in turn how they treated their child as a result of what that information led them to believe about their capabilities.

Several participants recounted experiences where medical professionals were very grim about their child's diagnosis. The picture doctors presented led parents not to expect much from their children and to prepare for a very difficult road ahead. This perspective may feed into why parents feel they need to be protective. When the diagnosis is described negatively, parents feel they must assume more responsibility from the beginning to do more for their child, setting up a pattern of "doing for" without giving them chances to develop those skills independently, even if they have that ability. Moreover, when parents do not see a natural progression, it does not present as a problem to be addressed because they are only seeing what the doctors told them to expect. This has consequences for how they parent, consistent with the expectations they set from an early stage. In addition to giving a diagnosis, participants explained how doctors only gave them a medical viewpoint about their child and any practical information was absent. In essence, they became overwhelmed by so much information about what could happen and things they should consider, but it was up to them to apply that information to their child specifically. This approach expands upon research that stipulates the treatment of children with disabilities focused on physical aspects of the disease: If the child's physical condition improved, the treating doctors consider the treatment effective. (Aran & Shalev, 2007) However, once again this attitude does not

consider the practical or emotional considerations that come with having a child with a disability. The parents in this study were left feeling very overwhelmed and not given appropriate emotional support or guidance by anyone in the field. They were also not given any guidance on raising a child with a disability from a practical standpoint.

As many parents explained, having a child with a disability evokes many emotions that are difficult to deal with. Often times as a way to cope, parents are taking on added responsibilities to control the situation and ease any hardships for their children influencing the attitudes they have towards their children and their capabilities. Presently, families feel there is a lack of emphasis on providing support to help cope with those emotions. In addition, parents feel responsible for managing their children's emotions and feel that if they do not support their child in that way that no one else will take on that role.

In this situation, parents put pressure on themselves to take on many roles in the name of helping their child.   In the present study, several of the children had physical needs that required more assistance than most children their age. Parents take it upon themselves to make sure those needs are met due in part to the fact that they have not been given the right resources or direction in how to help their child overcome certain things on their own. They also do not know how to go about directing their child in getting the resources that they need without assistance from their mom or dad. Worries related to physical access can be very intimidating and parents are often not directed to encourage their child in exploring how to address these things but rather taking it on themselves to make the situation more manageable.

In nearly every interview conducted, parents expressed hopes and desires for their children to be independent, less reliant on them, living on their own, finding jobs, going to school, etc. However, those expressed desires did not always translate to ways to foster that independence

because in those same families the children relied heavily on their parents. Parents struggled with wanting their child to be more independent but lacked concrete support or resources on how to help them achieve that goal. In some cases there was an effort to displace responsibility for one's own actions and consequences as well as future decisions by putting that responsibility elsewhere. For instance, many parents found hope in their religion and held a belief that God or a higher power would not only protect their child but also guide them to a better place in life. For many of the study participants, their religious beliefs acted as a lifesaver. They were able to hold on to the hope that they were not alone and a higher power would help to guide both themselves and their child down the right path. That sense of support offered a level of comfort unmatched in their everyday lives. While faith and hope saw several parents through trying times, in some cases the unfortunate side effect is by entrusting all outcomes to God, they can sometimes absolve themselves of the pressure and responsibilities of making difficult choices.

These findings are consistent with current literature that has explored how religion can affect individuals' actions and belief system. A study by Agorastos, Demiralay, & Huber (2014), describes the process as "beliefs about causality, in which individuals believe they have some degree of control over events that defy currently accepted physical laws." Previous research indicates that religious practices may have a persistent and significant positive influence on health, life satisfaction, and well-being. This positive impact is seen very clearly among people who are experiencing hardships or difficult life situations. For these individuals, religious faith may enhance the ability to cope with the life event. In some cases, the idea that our path in life is predetermined can be comforting because it brings hope for better outcomes. (Connor, Davidson, & Lee, 2003) Individuals use spirituality as a tool to search for purpose and meaning, According to Drescher & Foy (1995), "A spiritual approach can be helpful in restoring hope, and acquiring

a more balanced view about justice and injustice, safety and danger, good and evil." (p.3) It has been observed that stronger religious beliefs can lead to greater sense of control, and meaning especially in the face of a difficult or traumatic circumstance.

In addition to religion, some parents reflected the responsibilities of promoting independence to service professionals. The parents felt their duties ended at connecting their children to services. There is a need for greater attention to help parents feel more connected to the rehabilitation process and supported in their pursuits so they view these services as a helpful tool rather than fully relying on them for their child's growth and development. It is widely recommended that family members be actively engaged in the client's rehabilitation journey because evidence suggests that this is associated with better outcomes.

The ability of family members to fully engage in rehabilitation may be hindered by the barriers (logistical and psychological) they encounter. However, rehabilitation services can facilitate family engagement through a person-centered approach that provides support to remove barriers. The research literature has demonstrated that the support of family members is a key component to maximizing survivors' independence and psychosocial adjustment. Yet, paradoxically, family members often sacrifice their own autonomy and needs for social support in order to support the individual in rehabilitation (Stejskal, 2012). Barriers that affect family involvement include families' availability or flexibility, cognitive skills or level of understanding regarding disability, financial status, unrealistic expectations, not knowing how to process emotions of disappointment, and lastly, how experienced the treating therapists themselves are at involving family members (Galvin, Cusack and Stokes, 2008). Levack, Dean, Siegert & McPherson (2009) echoed psychological factors associated with lower family involvement in the rehabilitation process. The researchers found that family members had their own agendas and do

not always see eye to eye with rehabilitation staff. In addition, their expectations tended to be unrealistic and clinicians felt they had to limit family involvement to protect the patient. Overall research indicates that clinicians are more oriented to addressing the needs of patients rather than the family. Recommendations for achieving greater family involvement are detailed in the recommendations section of this chapter.

Another similarity among parents detailed in chapter four was the desire for their child to be happy. In a way, this came across as a fairytale like concept because that was their biggest hope, even if happy did not necessarily mean independent or self-sufficient. The disconnect here is that if they were to define happy outside of the realm of disability, most of us view happiness and being fulfilled and reaching certain goals in life that require independence, autonomy and self-reliance. The question then becomes how they are defining their child happiness when they do not emphasize the importance of acquiring the skills to achieve those attributes.

Research Question Two: How do parents perceive that they have modified their childrearing approaches and expectations for their children with disabilities?

When talking about expectations, parents were able to recognize that they had shifted their expectations once they realized their children were not attaining specific developmental milestones. This was due in large part to their needs becoming more apparent. Several parents described being surprised over the challenges their child ended up facing and as a result they were not as prepared for them, so again they felt increased responsibility to make that situation manageable. Perhaps if treatment professionals could find a way to better prepare parents for what lies ahead in ways that produce confidence rather than fear, parents would feel better prepared to equip their child to handle some of these situations independently.

Within the household, some parents admittedly set different expectations for their child with disabilities than for their children who are able-bodied. These findings expand on current literature that found that the presence of a physical disability could affect family dynamics, including those between siblings. In particular, the findings suggest that siblings share some of the same emotions as their parents, such as anger or guilt towards the disability. The study also supports earlier research that found that it is common for able-bodied siblings to be jealous of the attention their brother or sister receives from their parents. (Cuzzocrea, Larcan, Costa & Gazzano, 2014) Adding to these results, this study explored why some of those feelings exist and many parents expressed their expectations shifted due to feelings of guilt. They did not expect as much from their child with a disability because they felt guilty expecting more when their child might not be able to live up to those expectations. Parents also felt that their able-bodied siblings did not have to deal with as much hardship and therefore could handle more responsibilities.

This shift in expectations also was shown to have consequences for the children's social skills. Most of the parents interviewed were able to articulate that their child had not reached appropriate social milestones because of their parents' reluctance to let them socialize independently. Existing theories on parenting style have established that parenting style is a predominant factor in socialization because it is within the family circle that social learning begins and the first social contact is established. (Darling, 1993) While all participants were able to acknowledge that they did not give their child much social freedom, their intention in doing so was to be supportive. The issue then became that the child did not have the necessary opportunities to foster independence or reach typical milestones of social development.

Parents need the necessary supports if they, in turn, are able to support their child, while simultaneously giving them the skills to manage social situations on their own. Several expressed

concerns about their child needing to consider much more before participating in a social activity than the average child. If helping the child learn how to manage those things independently was built into the rehabilitation process parents might feel more confident in their childs' skills to participate in social situations independently and in turn develop their social skills from a practical standpoint rather than in theory. For instance, the topic of dating was avoided by many parents. They either did not feel comfortable discussing it at all or did not think their child's disability was going to allow for the typical dating experience. If, however, these children learn to socialize independently from a younger age, dating might come as a more natural progression because their parents would not be as intimately involved in day-to-day aspects of their social life.

This lack of discussion around dating also speaks to expectations parents may set for dating and sexuality concerning their children with disabilities. Previous research on dating and the sexual knowledge and experience of individuals with disabilities demonstrates the discrepancies in the education they receive from parents or educators compared to the general population. (Di Giulio, 2003). Oftentimes the subject of dating is taboo when in the disability community and parents hold the belief that having those types of conversations with their disabled child is uncomfortable and/or unnecessary. McCabe (1999) compared these and other sexuality related variables among people with developmental disability, people with physical disability, and people without disabilities. In this study, people with developmental disability had the lowest level of knowledge about sexuality, had less experience with dating, intimacy, and sexual interaction, and fewer opportunities to learn about sexuality (Cheng & Udry, 2002).

Although individuals with disabilities express an interest in knowing more about sex, research suggests that, unlike the non-disabled population, parents, siblings, and friends were not

main sources of sexual information (Ballan, 2000). According to (McCabe et al.,2000) "This suggests that sex is not generally discussed with parents, and so there is little opportunity to discuss the accuracy of sex information or to normalize sexuality as being just another aspect of the individual's life" (p. 122).

Traditionally, in the world of rehabilitation, sexual issues have been seen as a lower priority then issues that concern ones physical wellbeing. (Wazakili, 2009). In a study done by Wazakili (2009), disabled youth were interviewed on just how much they knew about sex and where their information was derived from. One of the children interviewed answered, "No one talked to me about sexuality. HIV/AIDS or other sexual issues. Not even family, friends or at school." This shows how important it is for professionals in the rehabilitation setting to be knowledgeable about how to address these key issues. (Wazakili, M., Mpofu, R., & Devlieger, P. (2006).

People with disabilities would benefit from gaining the knowledge to make informed choices when it comes to their sexual practices. They also need to know about their sexual rights and exploring sexual behavior and can only do so if they have access to the right information. When educators, family members, rehabilitation professionals and society as a whole, ignore or avoid issues surrounding sexuality, it becomes detrimental not only for the individual's wellbeing but also for their health and safety. Given that parents have expressed feeling uncomfortable engaging in this conversation, they may benefit from the assistance of rehabilitation counselor who is prepared to help navigate an open conversation surrounding disability and sexuality (Wazakili, Mpofu & Devlieger, 2009). Doing so could mean facilitating a conversation one on one, connecting the individuals and/or their family members to a mentor

that could help navigate the situation, and on a broader scale, expanding the rehabilitation experience to offer classes on human development and sexuality as related to disability.

In addition to dating and sexuality, the interviewer also explored other dimensions of continued development as children continue to age. When asked about what parents expected as their child continued to grow, parents had non-consistent expectations for the future. They were able to identify a desire for their child's continued development and could name their hopes, but were lacking the action steps to make those desires possible. Their lowered expectations cause them to believe that some of their child's expectations for the future were unrealistic and they were not comfortable setting them up for more disappointment. In addition, many struggled with when they should offer more support versus when they should encourage their child do things independently. In the interest of not wanting to see them struggle, most parents decided to offer more support even though they were aware that those decisions and actions would not encourage autonomy. Educating parents on expectations is key; the reality is that their child is only going to go as far as parental expectations allow. The fear of failure is evident but as a basic rule of humanity, we all learn from our failures and there is dignity in taking risks and knowing it is okay to fail and learn from those experiences (Usiak, 2004). Helping parents to shift those expectations from avoiding failure to embracing independence will help them afford their children more opportunities to grow.

Research Question Three: How do parents feel they could have been better supported through the process of raising their children with disabilities?

Parents expressed what they would recommend for others in similar situations. Several of these recommendations, if implemented, could help combat some of the obstacles that contribute to parents having lowered expectations. One of the chief recommendations was having other

parents who understood their situation available to them in some way so they can offer support. This again speaks to the emotional difficulties some of these parents were facing. Having someone who understood them on that level would help not only provide resources but also validate their feelings and help them to feel heard and understood. Taking care of themselves emotionally also includes finding a balance between being a constant part of their child's lives in being responsible for every decision versus teaching the child more skills and allowing them increased freedoms, so that parents are not constantly responsible, for not only the decisions that have to be made but also the outcomes. Parents or identifying the need to be more emotionally supported and peer-to-peer interactions as well as support groups is an avenue to help provide that type of support. Presently, most of the support parents identified came from professionals who support the medical model way of thinking. Peer to peer interactions as well as rehabilitation counselors can help provide a more well-rounded approach grounded in both the social model an independent living philosophy that could help provide emotional support while also encouraging independence.

They also expressed the need for stronger advocacy skills as part of the services their family receives. Rehabilitation professionals could support parents by ensuring they are fully informed, know their child's rights, what they are entitled to and how those resources shift as the child ages. Based on the responses to several of the interview questions, these added levels of supports would make parents more comfortable and self-assured in providing opportunities for more independence and self-sufficiency, as well as better equipping their children to self-advocate.

Overall, there is a need for the types of services and information parents are receiving to change. While medical support is necessary, parents are also expressing a need for practical information and support. From a medical standpoint, they expressed the need for doctors to be

more compassionate, provide information that is easier to understand, and present that information in a way that values their child as an individual and how it applies to the family specific situation rather than speaking in generalities. From a practical viewpoint, helping parents and families deal with the emotional burdens that come with the experience of raising a child with a disability is a vital component to them receiving the support necessary to help foster independence for their child.

Implications for Practice and Policy

While existing literature documents a relationship between parenting styles, overprotection and lack of autonomous functioning, few studies have explored why parents make the specific parenting decisions they make and how a child's disability impacts the parenting and family experience (Hartlage and Green,1972; Cappelli, McGrath, MacDonald, Katsanis, & Lascelles,1989; Homebeck et al. 2002; Aran & Shalev, 2007; Rybak, et al., 2016). Previous findings suggest there is need for a greater awareness and a deeper understanding of parental experiences through examining the factors associated with how and why parents make decisions as well as what they consider when setting expectations for their children with disabilities (Aran and Shalev, 2007 & Holmbeck, et al., 2002). Based on a review of the existing literature, the results of this study, and the experiences of the study participants, several key recommendations could significantly improve the support of parents, their children with disabilities, and the family unit as a whole in order to ensure children reach their full potential.

1. Parents would benefit from Programs specifically designed to support and prepare them, once they have learned of their child's disability diagnosis. Based on the experiences of participants in this study, essential components to such a program would include counseling, an overview of available supports, access to a

supportive rehabilitation professional that understands both the medical and

emotional components associated with the specific life experience, and other

parents that could act as mentors to help offer guidance and reassurance.

Implementation

The need for these types of programs of interventions is not new in our profession. These

types of programs to support not only children with disabilities but also their families has had a

place in rehabilitation distantly as her field has continued to progress. However, some of the

major barriers to implementing these types of programs are funding and public policy. To

effectively influence public policy and funding decisions rehabilitation professionals will need

to advocate more heavily for our profession, the contributions we can make to rehabilitation, and

the consumers we serve (Patterson, 2009). We need to accept that part of our responsibility as

professionals in this setting is to become advocates and take steps towards influencing public

policy and decision-making on a larger scale for the disability community.

2.   Presently, professionals are giving parents primarily medical

information about the child that does not include practical implications that would

help them to encourage independence or autonomy. Having a rehabilitation

professional available as a member of the rehab team to help navigate the raising

of a child in this situation would help fill that gap and also help parents feel more

supported and prepared.

Implementation

To achieve that goal, rehabilitation counseling as a profession needs to hold greater

value to the public and other professionals as we continue encouraging equality for individuals

with disabilities (Maki, 2005). An increasing number of rehabilitation jobs are needed to increase

the overall visibility of the profession. Contrary to popular belief, rehabilitation counselors'

scope of practice goes beyond providing people employment services to also include provision

of mental health support and family integration through the provision of independent living

services; as such the profession needs to continue to ensure that it is more visible and adequately

markets its unique skill set (Ethridge, Rodgers, & Fabian, 2007). The rehabilitation counselor's

knowledge, skills, and service delivery are comprehensive and applicable to almost any group,

including people who do not meet the definition of having a disability. As such, rehabilitation

counselors need to cultivate an appreciation for the strengths of their diversity in all types of

work settings and job titles. (Patterson, 2009). We need to individually and collectively market

the profession of rehabilitation counseling so that it is valued, respected, understood, and a

central part of society. In addition, research in our field needs to concentrate on the benefits to be

derived from rehabilitation counselors being more predominant within a medical setting.

3. It is essential that rehabilitation professionals fully communicate expectations as
   to how parents should be involved in the rehabilitation process and not place all
   the responsibility on service providers. A team approach should involve parents to
   help ensure their child gains the skills necessary for independence early on.

Implementation

Previous literature details ways to encourage families be more actively engaged in the

rehabilitation process including increasing family support in providing explicit structuring of

services to include (i) early engagement, (ii) meeting cultural needs, (iii) keeping families

together, (iv) actively listening, (v) active involvement, (vi) education, (vii) skills training, and

(viii) support for community integration. (Foster, Armstrong, Buckley, Sherry, Young, Foliaki &

McPherson, 2012). Implementation of these support strategies are individualized based on the expressed needs of each family.

> 4. For children specifically, it would be beneficial to teach the skills necessary to socialize as part of the rehabilitation process.

Implementation

This would require taking our approach beyond the medical perspective to one that is well rounded and comprehensive to rehabilitation, including but not limited to counseling services that specifically encourage and help navigate independent living. This shift in services could be made possible by increased funding to children's rehabilitative services and centers for independent living that could support such a comprehensive service program by encouraging the independent living philosophy from an early age. In addition, policy reforms would be necessary to introduce supports within the school system so teachers have the skills and knowledge necessary to encourage more independence, give children the opportunity to make their own decisions, and work with parents as advocates to determine the best situation for the child.

Integrating the Independent Living Philosophy into the Rehabilitation Process

As rehabilitation counselors, we aim to facilitate independence and autonomy, holding the belief that everyone should be supported in living life to his or her full potential. To achieve this, we must recognize the relationship among all areas of a child's life, including social, physical, emotional, cultural, and vocational aspects, in addition to recognizing how these can work together to best serve the client. Individuals with disabilities have unique needs in a counseling relationship that counselors need to consider (Bent et. al, 2002).

As rehabilitation professionals, we aim to provide the individuals with whom we are working with genuineness, unconditional positive regard and empathy, which enables them to

feel comfortable enough to express fears and concerns. Then, the hope is that they will eventually be inclined to recognize the impact of the disability upon their self-concept, and acknowledge the discrepancy created between their current situation and how they view their ideal selves (Warner, 2002). As a result, these individuals can then better understand the strengths they possess, which will help them to set and reach goals consistent with that ideal image and to reach a point of self-actualization and acceptance. Employing these practices with children and families from the start of the rehabilitation process helps to ensure that children develop self-acceptance and a healthy disability identity from early on in life.

For individuals with disabilities it is vital to stress the importance of taking control and setting goals and expectations that encourage typical development, because individuals with disabilities typically do not have the autonomy to make these types of decisions (Sanders, 2006). It is imperative to ensure the client always has an opportunity to make an informed choice and that professionals and parents respect his or her autonomy and judgment. (Parker et al., 2000).

Rehabilitation professionals who apply the independent living perspective into their practice provide the opportunity to highlight elements from the Rogerian, existentialist and cognitive-behavioral perspectives and put independence and autonomy at the forefront. This philosophy is rooted in deeply held values and beliefs as to how people with disabilities can acquire and maintain personal independence. Data from the current study suggests parents may benefit from this approach being implemented into their child's rehabilitation from a young age as it gives them support and guidance on how to encourage independence and implement these principles.

Development of New Theory

Parental Expectations and Decision-Making Concerning Disability (PEDD) Model

Overview:

Parenting a child with a disability comes with a unique set of challenges, and both parents and children need to find the most effective ways to deal with them. The present study examined and identified what factors parents feel influence them in making decisions about their child and the expectations they have for them. The finding were used to create the PEDD model, graphically displayed in Figure 1. This model examines those factors and the role they play in parents making decisions for their children that ultimately determine the expectations they set for them. The different domains highlighted in this model illustrate what influences expectations and decision-making and how each of those domains play a part in predicting outcomes for children with disabilities and their families. Parents and their children have needs that are not being met; hopefully, using this model is the tool to ensure we are addressing all components of the family life as they relate to the rehabilitation experience will help us provide more \comprehensive service that ultimately promotes independence.

Domains within This Model

The central domain of this model is expectations and decisions. All other domains are connected to the central category and play a role in influencing those outcomes. The first section of the model includes the domains that directly link to the family's experience with disability and in turn affect emotions and/or decisions. These contain (a) gathered information- (ai) information parents had pre-disability experience and (aii) information they gathered while going through the process of raising a child with a disability. Each of these categories connects to (b) experienced emotions- emotions evoked by experiences surrounding the child's disability.

The second section within the model details personal and external factors that directly connect to influencing expectations and decisions made about raising a child with a disability. These include (c) Supports- such as rehabilitation counseling, practical information and peer support. This domain then connects to having the steps necessary to support overall goals of the family and child. Lastly, (d) personality and resilience is the domain that examines personal factors of the parents themselves that influence what they consider when making decisions and setting expectations for their child with a disability. Figure one (appendix B) is a visual depiction of the model.

Model Components Section One

Gathered information:

This domain of the model has two parts: (a) information parents have gathered prior to their child's diagnosis including cultural influences, religious backgrounds and previous experience with disability and (b) information they received after the child's diagnosis primarily for medical professionals. Cultural and religious backgrounds were seen to have tremendous influence on how parents processed emotions related to disability diagnosis that in turn influence how they make decisions and the expectations they set. Cultural backgrounds may have made experiencing disability more difficult because their culture was not as progressive or forward thinking. For others, they were shown to rely on cultural and religious views as a source of positive emotions that help them handle the situation and accept guidance in different ways when deciding what decisions to make concerning their children. These are all components that influence information parents have gathered prior to their child's diagnosis as well as their personality and level of resilience.

Information received after the diagnosis is a critical component to helping parents form

expectations and the decisions that they make. For instance, many medical professionals paint a

grim outlook on disability that tells parents from the beginning not to expect much from their

children. When the diagnosis is described negatively, parents feel they must assume more

responsibility from the beginning to do more for their child, setting up a pattern of "doing for"

without giving them chances to develop those skills independently, even if they have that ability.

This also influences decision-making and expectations because when parents do not see their

children progress in a normal pattern of development, they view this as normal and do not seek out

strategies for further advancement. (Aran & Shalev, 2007)

Emotions

All sources of gathered information allow parents to predict what they think their child's

future might look like. As they are putting together this picture, they experience many different

emotions that helped to dictate how they are going to treat their child and proceed moving

forward. For instance, fear is a predominant emotion that affects setting expectations in making

decisions concerning children with disabilities. The presence of disability seemed to lead parents

into presuming from the beginning that their child was not safe and led to a fear that their

children may fall victim to bullying, negative reactions from the public and difficult emotional

reactions. That fear contributes to parents trying to manage their child's experience to protect

them from emotional harm. As previously detailed, the literature does show that these concerns

are legitimate however; this fear also led parents to be more overprotective setting lower

expectations in making decisions that gave their child fewer opportunities to progress.

Oftentimes as a way to cope with difficult emotions, parents are taking on added responsibilities

to control the situation and ease any hardships for their children, influencing the attitudes they

have towards their children and their capabilities. In essence, the unavailability of an outlet for

parents to express or deal with their emotions is hindering their ability to clearly think through

the decision-making process and set expectations for what they want their children to achieve.

Model Components Section Two:

Personality and Resilience

This study identified several factors related to how parents make decisions and

inform their own expectations concerning children with disabilities. In many cases, parents had

very similar experiences and reactions between them, but there was nevertheless some variability

among the interviewees that coding did not account. In developing this model and looking to

account for such variation, I have determined that these variations owe themselves to a myriad of

unique personalities. Each parent I interviewed possessed their own personality that influenced

how they reacted to their child's disability. Each parent's level of resilience likewise played a

role in their family's situation. Given that each family's situation is different, the ways they

adapted were highly variable. "That ability of the family to adapt, and build on present strengths

offers opportunities for the family to maximize quality of life. This is resilience." (Appleby,

2014). Research shows that resilience indeed plays a key role in a parent's ability to adjust to

their child's disability, in addition to their ability to seek out appropriate supports. In turn, those

supports are necessary to make positive change in their social lives, manage high levels of

dissatisfaction and maintain optimism about their child's future (Heiman, 2002). In this way,

resilience levels of parents are foundational to children's development.

The present study, like much current research, demonstrates just how important these

supports are to individuals with disabilities and their families. As such, it is important that we as

rehabilitation professionals recognize our role in helping provide supports that address common

barriers, at the same time helping parents to maximize their resilience (Stuntzner, & Hartley, 2014). Families have clearly expressed the need for a strong belief in their child and his or her potential for success. Providing the resources, supports and programs of intervention to help build those things alongside the family's resilience will help us better serve client families (Heiman, 2002). If the rehabilitation profession can focus on specific interventions that define better supports that experts have designed to help families adjust to disability, we can help individuals and their families increase resilience and better cope with their emotional and physical struggles, achieving more positive outcomes (Stuntzner, & Hartley, 2014).

Support:

Throughout this study, parents identified several avenues of supports, or lack thereof, that in turn had great influence on the decisions they made and the expectations they set. For instance, while many parents felt supported from a medical standpoint, deficiencies in practical information and how to apply strategies to help their children, made it difficult to know what expectations were realistic. Expanding the support network for parents, would create opportunities for greater access to practical information that helps to support them in knowing they are on the right track in the parenting decisions that they are making. Two ways to help expand that support network include peer mentoring and including counselors as part of the family care team during the rehabilitation process. Having other parents who understood their situation available to them in some way can offer emotional support. Having someone who understood them on that level would help not only provide resources but also validate their feelings and help them to feel heard and understood.

In addition, rehabilitation counselors are in a unique position to offer support to families because of their unique skill set within the disability population. Rehabilitation counselors also

have the ability to implement strategies that immerse families deeper into the rehabilitation process in hopes of helping them to be actively engaged and as a result feel more supported. A team approach should involve parents to help ensure their child gains the skills necessary for independence early on. (Foster, Armstrong, Buckley, Sherry, Young, Foliaki & McPherson, 2012). How we achieve this depends on the expressed needs of each family.

Future Research

Future research is necessary to give voice to the experiences of children with disabilities. The following approaches could expose additional strategies to promote a better, more well-rounded and educated family experience.

1. Engaging in research that illustrates the experiences of young adults with physical disabilities and exploring how they view their level of autonomous functioning and what emotional and physical factors contribute to more or less independence.

2. The participants in this study were mothers of children with disabilities. Researchers can gain a new and interesting perspective by interviewing fathers or other caregivers in a similar manner to see if and how viewpoints shift.

3. Additional research is needed to explore how families embrace disability as well as the disabled individuals themselves and the impact this has throughout development.

4. Various religious and cultural values influenced the responses of the study participants; this warrants further research into the impact these factors have on individuals with disabilities and their families.

5. Future research is needed to test the effectiveness of the Parental Expectations and Decision-Making Concerning Disability (PEDD) Model.

6. The present study did not consider the school environment. Further research into the child's experiences within the school system in order to learn how the school environment encourages or discourages independence is important so the necessary policies are implemented.

7. Additional studies could provide a greater understanding of how to empower children with disabilities and their families to set higher expectations, particularly as those expectations relate to independence and autonomy. In addition, further research on how to implement independent living principles most effectively could open an opportunity for counselors in the rehabilitation and mental health profession to serve these clients more effectively. Further research into the use of traditional counseling techniques and infusing the independent living philosophy into the process is needed to help rehabilitation counselors see the importance of fostering more independence and dignity for clients as they move through life with a disability and face the associated challenges.

Conclusions

All parents, including those of children with disabilities, share common ground in that they want what is best for their child. While some of the challenges parents of children with disabilities face are unique, many are universal and we in the rehabilitation profession could do a better job recognizing such challenges with the intent of providing better services. During interactions with medical providers, parents would benefit from the provision of services that transcend medical management to include more concrete and individualized services for families. We also need to expand the services children are receiving to include a more practical

skillset from an early age, so their parents are more confident in their ability to make decisions on their own.

Families whose children have disabilities are willing to and capable of providing the best care possible. What appears to be missing is the education and emotional support to channel their loving energy into setting high expectations and knowing how to effectively plan for and reach goals while at the same time be confident in their child's abilities, affording them opportunities to take control of their own lives. In addition, it is critical to address systematic barriers related to support, both emotionally and financially. The system needs to prepare to fund programs that help create an environment that sets parents, their children and the disability community up for success.

Appendix A

INTERVIEW QUESTIONS

1. Can you describe your views on disability before having your child?

    a. What exposure, if any, did you have to individuals with disabilities?

    b. How did that shape what you thought about individuals with disabilities?

2. How, if at all, has your perception of disability changed since you had your child?

    a. What were your expectations about having a child with a disability before your child was born?

    b. In what ways have those expectations changed?

3. Tell me the story about when you first learned about your child's diagnosis.

    a. How did you feel? Why?

    b. What information where you given about the disability?

    c. What if anything, were you told about their quality of life predictions?

4. What was your biggest fear or worry at that time? Why?

5. What, if any, resources were you given after your child was diagnosed

    a. Did you feel you were given enough information and/or support? Why or why not?

    b. Is there anything you can think of that you wish you were given or told?

6. As your child has gotten older, have your expectations of/for them changed? Why or why not?

7. How do you make lifestyle decisions concerning your child? (this question and follow up depend on age)

    a. Example have you discussed dating with them? Please give an example.

    b. Describe a typical outing they partake in with friends

    c. How are they planned?

    d. How if at all is your child included on making health care dictions?

8. Describe a time when you were not sure what the right decision was between letting your child handle a situation independently or intervening to help guide them.

    a. Why was this situation hard for you?

    b. What factors did you consider?

    c. Ultimately, how was the situation handled?

    d. Do you feel that was the right call?

9. If there are other children in the house, please give me some examples of how their day-to-day life is the same or different?

    a. Describe the chores that are being done (if any). How are decisions about chores made in your house?

      b.   Describe the daily activates your child participates in. How are decisions about activities made? Who is involved in the decisions?

10. What are some of the things your child has expressed interest in doing as he or she gets older?

      a.   What conversations have you had about going to school? Please give examples.

      b.   Things they'd like to pursue

      c.   What makes you feel these things are attainable or not

11. What aspirations do you have for child?

      a.   Where would you like to see them 5, 10, or 20 years from now

      b.   In what ways do you hope to see them progress

Appendix B

Figure 1: Parental expectations and decision-making concerning disability (PEDD) model.
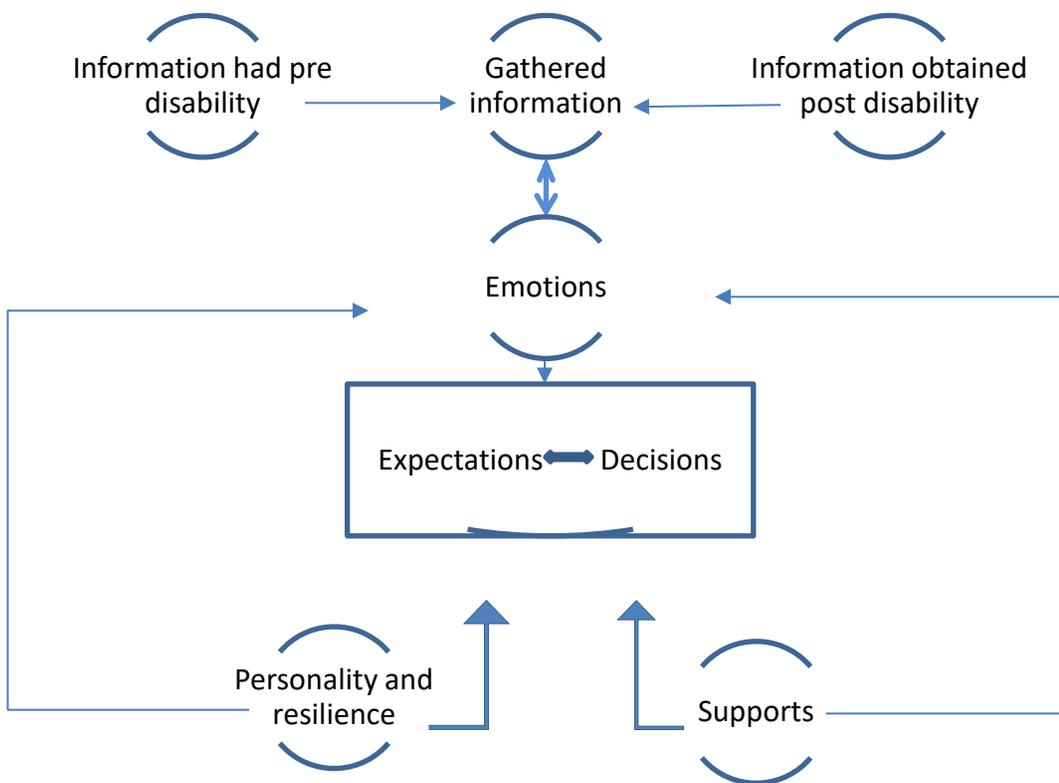
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