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Parenting Decisions and Disability: What Rehabilitation Counselors Should Know

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The purpose of this qualitative study was to gain a better understanding of the experiences of parents raising a child with a disability. The researcher collected qualitative data through multiple interviews with parents who had children with disabilities. The results of this study indicated that parents perceived that both the parent and child had needs that were not being met and found ways in which they were empowered to make certain parenting decisions. Three major themes emerged from the data: 1) desire to protect, 2) the influence of medical professionals, and 3) a sense of passive hope for their children and other families. Parents shared what appeared to be lacking was sufficient education and emotional support to help them channel their loving energy into setting higher expectations for their children. They needed help to effectively plan for and reach developmental milestones, and support for confidence in their child's abilities to afford them opportunities to take control of their own lives. Several recommendations were suggested to help rehabilitation professionals better support parents raising children with disabilities.

Keywords: Parenting, disability, parenting decisions, children with disabilities

Parenting a child with a disability is not always an easy task. Each disability comes with a unique set of challenges, and both parents and children need to find the most effective ways to deal with them. Researchers have found that parents often assume added responsibilities to make their disabled child's life as easy as possible, and that parents did not require as much accountability or behavioral autonomy from them as they would a typically developing child (Sanders 2006, Locke et al., 2012).

Sanders (2006) indicated 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 the children's exposure to difficult situations, which prevents 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, tended 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).

Traditionally, the treatment of children with disabilities has emphasized management of the physical aspects of the disease, and physicians measure treatment efficacy primarily by means of physical improvement (Centers for Disease Control and Prevention, 2020; Holmbeck et al., 2002) However, several researchers have shown that this approach to disability management tends to lead to overprotection rather than fostering autonomy and encouraging independence (Cappelli et al., 1989; Hartlage & Green, 1972; Holmbeck et al., 2002; Segrin et al., 2015). 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.

Cultural and societal responses associated with disability and raising a child with a disability are often informed by the medical model of disability. Our society predominantly operates from the medical model perspective of disability, driven by diagnosis. A physiological difference, impairment or injury are viewed as deficits or a failure of a bodily system (Goodley, 2016). The central focus of this model lies in its location of disability as an individual problem (Swain et al., 2003). The goal is to fix what is "wrong" with the individual. Therefore, solutions are focused on fixing, normalizing, and cure even when the impairment does not cause pain or illness. Individuals are viewed as abnormal, less-than, weak, and incapable. Corrective surgeries, therapies, interventions, and devices are imposed by medical professionals (Goodley, 2016). This perspective leads people to believe that disability is inherently a bad thing that needs to be eliminated (Vash & Crewe, 2003). People with disabilities have been explained as divine punishment, karma, or moral failing which leads to responses like shame, pity, fear, and avoidance. In an attempt to rid disability from society, people with disabilities have been euthanized, institutionalized, and sterilized (Goodley, 2016). Culture, religion, and the individualistic approach tend to reinforce the dominant medicalized view of disability.

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, Segrin et al., 2015). 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 daily, to learn specific styles and practices that nurture the skills required for independence and maturation.

Researchers have shown that parenting style is one of the most important family variables in a child's psychosocial development. Cappelli et al. (1989) found several significant correlations between overprotection and poor psychosocial functioning in children with cystic fibrosis. Similarly, Hayden et al. (1979), Holmbeck et al. (2002), and Bayu & Kusmariyatni (2019) 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 have been consistent across the available literature regardless of the type of physical disability the child experienced. Adults treated children with disabilities differently from their peers and, as a result, children with disabilities did not have the same life experiences.

Purpose

Available literature has established a correlation between parenting style and social maturity and the negative impact it has had on children with disabilities. However, the literature currently does not address the question of *why* parents make choices that overprotect their child and limit their development of autonomous functioning. The results of the present investigation provided a better understanding as to why this correlation exists and may 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 their social skills which help increase overall autonomy and therefore independence (Mirabile et al., 2018). Furthermore, this study provided a deeper understanding of the dynamics associated with raising children with disabilities, which in turn addresses the 'what', 'how' and 'why' associated with the choices parents make in raising their children with disabilities.

Terms and Definitions

Autonomous Functioning

Behaviors associated with a child's ability to be more independent, or display autonomy have continued to define the overall construct of autonomous functioning. Research suggests behavior that is more autonomous has numerous positive outcomes for children as they grow and express increasing levels of maturity (Roth et al., 2007). When autonomous, individuals experience their behavior as self-endorsed and congruent with their values and interests.

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; Beebe et al., 2000). When an individual is socially mature their behavior is in accord with standards and norms for a person of that age.

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 (Pringle, 1951; Javady, & Zeinali 2019). Several characteristics determine the processes through which parenting style influences child development, including but not limited to 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.

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 many parents allow their child less autonomy (Aran et al., 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.

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). Disability studies scholars examine disability and independence as a social construct, rather than a physical characteristic. Consequently, one's physical abilities or developmental milestones do not determine the presence or absence of independence. These scholars use the term "independent" to indicate someone who has taken control of their life by choosing how their life is led, rather than what the person can do without the help of others (Thomas, 2004).

Researcher Identity

The researcher was born with Cerebral Palsy, an experience the researcher shared with the participants' families. The researcher's mother will be the first to tell you that she did not initially know anything about raising a child with a disability—she raised the researcher as she would any other child.

This mindset illustrates the premise of how the researcher grew up and demonstrates the viewpoint that guided the researcher from a young age. Until the researcher became older, they were not aware that they were different.

With personal experience, the researcher was able to capture the participants' stories more vividly and was more sensitive to the difficult subject matter. With this in mind, the researcher was careful to ask neutral interview questions and ask clarifying questions with the intent of understanding participants' perspectives, rather than sharing their own thoughts and experiences in order to avoid bias.

Research Questions

This study explored parenting styles and attitudes as they related to raising a child with a physical disability. Three questions guided this investigation:

(a) What factors did parents feel influenced them in 1) making parenting decisions about their children with disabilities that involved questions about autonomy vs. protection and 2) the expectations they had for their children?

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

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

Method

With approval from an Institutional Review Board, the researcher collected qualitative data using grounded theory. 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 analyzing data. 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 depth or where a new point of view on familiar topics appears promising (Milliken, 2010). Through multiple interviews, parents of children with disabilities were asked questions about their experiences parenting a child with a disability, how they perceived their parenting approaches have shifted since their child's diagnosis, what they envisioned for their child's future and what, if any, further information would have been helpful in adjusting to their child's disability.

Participants

Participants were parents of children attending the Children's Clinic of Southern Arizona. All families resided in Arizona and came from similar, working class sociocultural backgrounds. The lead researcher's requisite knowledge and understanding of the cultural values related to disability helped to successfully reach data saturation. This clinic serves children all over southern Arizona for both general pediatric care as well as children with disabilities. Parents included in the study were those of children whose disability was primarily physical, meaning any disability or chronic disease that left the child with a physical impairment such as not being able to walk, trouble with movements, and seizure disorders.

Table 1
Participant Characteristics

Parental Role	Child's Age	Child's Gender	Child's 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

Design and Procedure

Recruitment

The sampling methods were a mix between convenience and non-probability sampling. Non-probability sampling as Merriam (2009) describes it was most appropriate, as generalizability is not a goal of qualitative research. This method was purposeful because the researcher sought to understand a given population and used a criterion-based selection to create a list of attributes essential to the study to find a unit matching the list (Merriam, 2009). With this in mind, selected families were those that were able to best answer the research questions.

There were 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 useful for the goal of achieving saturation. The researcher stopped data collection once data saturation was reached which included 12 participants (Seidman, 2019).

Procedure

The researcher conducted semi-structured interviews 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 to help provide an in-depth account of their experiences. The questions helped ascertain how parents viewed their child and treated him or her as compared to their other children, if applicable. The interview also included questions related to parents' feelings about certain situations and asked 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 everyone's experience to gain as much information as possible and be open to any previously unidentified constructs or factors to inform the research questions sufficiently.

Data Analysis

The researcher transcribed all interviews and observation notes for further analysis. Data was analyzed using what Merriam (2009) described 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, the analysis and coding of the data produced higher-level themes, concepts, and assertions. This process began with assigning reasonable codes, categories, and themes suggested by the first instance of narrative text or other observations. In coding the data, the researcher followed a grounded approach (Corbin & Strauss, 2011). The researcher explored the data openly with no preconceived notions.

Limitations of the Study

One notable limitation in this study relates to the use of a convenience sample. The researcher only collected data from one site and therefore the findings may not be representative of the general population. 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 remained subjective.

Results

In response to interview questions, the researcher identified several themes and subthemes related to each research question following data analysis. Data illustrates the main themes of 1) desire to protect, 2) the influence of medical professionals, and 3) a sense of passive hope for their children and other families are shared.

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 their 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 everyday 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, feared other children would 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 shared these concerns but was 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."

In addition to bullying, parents 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 those reactions can be frustrating, and they wanted to help their children through those experiences. For instance, one parent felt that people treated her son differently because of his disability.

> One of the biggest things, when we are out socially, is he does absorb a lot of attention from people . . . they stop us when we are walking and try to pray for him. It is just a lot of unnecessary attention that I know is coming from a place of love, but it is very difficult because he is not being treated equally.

Parents shared that often people were unsure as to how to react to their children, so they needed to be there to oversee interactions.

> Some people do not know what to say or do. I think they are just afraid. A lot of people do not know how to approach my son. You know, they stare, or they look at him—they do not feel comfortable enough to go up to him.

As part of protecting their children, parents expressed that they did not let their children be alone or do things independently. The parents made sure there was always someone there to assist him or her physically or in social situations to ensure the child's safety. There was a constant desire to keep them safe, which in turn affected how parents treated them. Several parents admitted to being more protective of their child with a disability because their 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 is what any parent wants for their child, especially when their child has a disability, because they are very gullible. I do not know if that is the right word. They are easy prey because they want to be very understanding and very giving, and people use them for that.

In general, parents felt their children with disabilities were more susceptible to harm and did not have the tools necessary to protect themselves. They needed constant monitoring and looking after because their social skills oftentimes were not up to par with their peers. One parent felt these characteristics created somewhat of a cycle for her daughter. She saw her daughter as more gullible and less socially aware but also said 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 demonstrated her thoughts:

> Parent: We do not leave her with caregivers that we do not know. We must totally trust them before they are 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 is 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?
>
> Parent: Because I think she has been so protected; she has 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.

The Influence of Medical Professionals

Several parents discussed the influence of the information given by medical professionals as well as the experiences the parents themselves had surrounding their child's diagnosis. These factors all had an impact on parental attitudes toward disability and, in turn, how they made decisions concerning their children.

Medical Advice and Communication

The parents who were interviewed had regular interactions with medical professionals. The interviews made it clear, through the responses to several questions, that information that came directly from the doctor had significant influence over a parent's behavior or actions toward their children. Every disability had different experiences attached to it, and each doctor handled conditions somewhat differently. Nevertheless, the interviewees exhibited some similarities and influences to consider when they received 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. When information was provided, disability was often framed as a negative characteristic aligning with the medical model of disability. It was up to the parents themselves to draw their own conclusions, and in many cases, do their own research.

One parent recalled 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 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. One parent said "I was told not to expect much. It was sad. They said he would not have a normal life, he would not walk, or talk" Another parent recalled 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 their capabilities.

Along with presenting parents with a diagnosis, some doctors discussed terminating the pregnancy as an option because of the hardships that lied 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. Another participant recalled the conversation with her doctor,

> Interviewer: He asked, do you want to terminate?
>
> Parent: 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 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." 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. One parent shared an example:

> There are resources out there, but nobody knows where to go to because schools and other agencies do not want to tell you because they do not want to risk having to share money or they do not want to have to search for things—they do not 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 inde-

pendence or what to consider when forming expectations for the child throughout the development process.

One parent 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 cerebral palsy 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.

Again, another parent echoed with a similar experience in talking to the doctors, "you got this very medical viewpoint, but nothing about my kid as a person."

Personal Experiences Surrounding the Child's Disability

The medical aspect of the disability evoked many emotions in parents that were often difficult to process. Often to cope with the feeling of a lack of control, parents took on added responsibilities to attempt to exert control, in this way impacting the attitudes they had towards their children. Parents discussed how they were responsible for tending to their children's' emotional needs surrounding medical issues. Parents felt an added sense of responsibility to support their children specifically because of their disabilities. They felt there was an additional level of need from their children because the associated medical issues were very complex and frightening. Parents felt that by having more of a presence they could "provide more of an explanation and ease fears."

Parents went through many emotions after their child was born with a disability, and the diagnosis significantly affected their view of the future. In discussing this throughout the interview process, parents reflected on how their parenting approach shifted. For example, one parent spoke about how she felt when her son was diagnosed. "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."

Several parents shared similar feelings of guilt and a sense of loss because the disability was unexpected. One parent stated, "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."

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 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 one parent noted,

> 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 has 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. 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 and remember traumatic experiences from the day their child is born:

> I almost lost him at 16 weeks, so they stitched my cervix, and I was on bed rest, and he still came early. He was 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 did not know, but once he was born, I did not leave his 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:

> 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 continued to make concerning their child moving forward.

A Sense of Passive Hope for Their Children and Other Families

Throughout the interviews, parents expressed the desire for their children to live a full life. Often, when asked to elaborate, parents shared that a full life consisted of the child becoming more independent and less reliant on their 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 the 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. One parent contained her desire for her daughter to find independence one day, but at the same time 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 had "never been exposed" to difficult situations. Those same situations, for most teenagers, help foster a sense of autonomy and self-reliance (Ryan et al., 2006).

In most cases where parents expressed a desire for their child to have more independence, they also acknowledged that they were not at that point in their lives. For instance, one participant acknowledged that her son, who was 18 years old, could have been living independently. While she wanted that for him, she felt he still had a lot more to learn before he would be able to do so successfully. She illustrated 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 maintained a paradox in that she shared such things, but at the same time expressed her desire to see him independent someday. Another parent purveyed a similar outlook, whereby she encouraged her granddaughter to pursue her dreams and be independent but at the same time declared, "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 religion 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, parents felt their children's fate was already decided. As one parent explained:

> 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 is 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 shared the belief that if it were God's will for their child to be independent, it would happen. This belief helped them to 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 having a level of faith was extremely helpful in allowing them to feel less overwhelmed by their child's disability. One parent expressed that being able to put their faith in God was a lifesaver. "As a Christian person, it's 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." The parent said that, even in moments of despair within her family, their faith saw 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 which would be enough to make children be independent and flourish. As one parent 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, the most important piece was happiness. That was their biggest hope—even if happy did not necessarily mean independent or self-sufficient. As one participant said, "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." Two other parents 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.

Many of the above comments reflect the dominant medical model framework of disability where the focus lies on fixing the individual through services and surgeries. There was also an over emphasis on independence meaning doing things alone rather than looking for ways for the child to be in control of their care. Parents wanted their child to achieve independence but often shared language that reinforced negative stereotypes and misconceptions surrounding the disability community often and consistent with the medical model (Swain et al., 2003). Other parents seemed to focus on the idea of happiness as a goal but there was a lack of discussion on how happiness would be achieved.

Developmental Milestones

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, their anticipations shifted. One parent said there were considerations she had to entertain for her son that most parents did not need to think about for their children:

> That plays a part in how much to expect for him, you must 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 couldn't control the unknown.

While parents in this study recognized that their children were not always reaching typical developmental milestones, they noted their expectations shifted in favor of manageability according to their child's individual needs. One parent 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 several 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. One parent stated "the expectations are different. I have higher [expectations] for her [sibling] than I do him, just because I know that she can do more things without assistance than he can. it's so different with both kids."

Two parents also admitted to treating their children without disabilities differently and holding them to higher expectations.

> 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.

Another parent also discussed how she did not expect as much from her son compared to her other children because he had been through so much that she wanted 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 typical children, "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 expressed some level of concern around their disabled child's socialization and everything they needed to consider with regard to social activities. While many children grew into independently participating in outings and social events, the parents shared that they felt they needed to be present if their child was to remain safe. One explained,

> 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 are 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; and tried to avoid answering the question. An interviewee provided 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 described that their teenagers had not expressed interest in dating yet, so the conversation had so far been absent. When discussing her daughter's dating habits, One said she had not discouraged dating and had always been open to talking to her daughter. However, she considered her daughter would have different experiences than most girls her age because of 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: The Struggle with When to Push, When to Assist, When to Let the 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 the researcher what their expectations for their child were, but there were some discrepancies between whether those desires were realistic. One participant knew what her son wanted to do but also did her part to ensure that his goals were what she considered achievable. She stated, "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." Another seemed to have high expectations for her daughter and 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." Nevertheless, this parent is like so many other parents struggling with when to push and when to assist or let children try things on their own to be more active in making decisions about the future—especially when emotions were challenging to navigate. As she 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.

Most parents shared that they struggled in this way and aired 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 was appropriate to push them. There was also the added emotional burden that came with medical uncertainty, and some parents did not provide the freedom for their children to address indecision on their own because of the added emotional stress associated with making decisions or the possibility of making the wrong choice.

Additionally, a parent shared that she also had a difficult time making some decisions because she wanted her son to develop as typically as possible and reach milestones like his peers, but she struggled with wanting to offer more support. She shared, "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 tried to offer their child more opportunities to make decisions and communicate about desires and needs. This fostered and encouraged independence. As one of them 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 were conscious of still being involved in all major decisions concerning their child.

Parents' Recommendations and Hope for Others

Parents expressed recommendations for others in similar situations. In certain cases, not having appropriate resources influenced their parental approaches. For example, several parents said that if they had mentors to help guide them, they would have made different parenting decisions. According to the parents interviewed in this study, having other parents who had gone through the same thing to share resources and offer support would have made a significant difference in their parenting approaches. Seeing how other parents handled similar situations would have given these parents ideas as to how they could handle their own situation. As for their children, the parents shared that it would have helped their children to interact other individuals with disabilities and may have acted as a motivating factor to help them continue to push themselves. Several participants confirmed this need for a role model, "like a mentor, a peer to peer, there to help and give advice."

Other parents described how helpful it would have been to have additional resources. Parents shared that access to parental resources was crucial in both encouraging independence of their 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. They shared the desire to have better resources available to prepare their children to be more independent. One parent stated, "there were various resources that I should have had. 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:

> 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 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 pushed more for their children and fought for them to reach their full potential. One parent 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 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 lay in finding a balance for one's children, given all the "extra things" they needed to deal with. Another parent illustrated this point:

> From a mom, I am 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 are 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 is, I think, the most important advice I can give someone that's starting out in this world.

Discussion

Some key interventions could significantly improve the support of parents, their children with disabilities, and the family to help children reach their full potential.

1. *Parents would benefit from programs provided by rehab counselors specifically designed to support and prepare them once they have learned of their child's disability diagnosis.*

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 & Joseph, 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. *Therapy teams should include a rehabilitation professional who is available to help parents navigate the process of raising of a child with a disability to help parents feel more supported and prepared.*

Presently, professionals are giving parents medical information about the child that does not include practical implications that would help encourage independence or foster autonomy. 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. 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. A 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. It is essential that rehabilitation professionals fully communicate expectations and encourage parental involvement in the rehabilitation process. This type of approach will challenge the idea that all of responsibility falls on services providers. Parental involvement can also help ensure children learn the skills necessary for independence early on.

3. *For children specifically, it would be beneficial to teach the skills necessary to socialize as part of the rehabilitation process early in the child's life.*

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 to encourage the independent living philosophy from an early age could be made possible by increased funding to children's services within Centers for Independent Living. Policy reform is necessary to introduce supports within school systems, so teachers have the skills and knowledge necessary to encourage more independence, opportunities for socialization, opportunities for children to make their own decisions, and to work with parents as advocates to determine the best situation for the child.

Integrating the Independent Living Philosophy into the Rehabilitation Process

Individuals with disabilities have unique needs in a counseling relationship that counselors need to consider (Bent et al, 2002). 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; Locke et al., 2012). It is imperative that a child with a disability always has an opportunity to make an informed choice, and that professionals and parents respect their autonomy and judgment (Holmbeck et al., 2002). Integrating this type of philosophy into the rehabilitation process is one way we can strive to avoid inherent biases against people with disabilities.

Below are additional recommendations for rehabilitation counselors to help shift the dominant cultural response to disability and expectations of children/clients with disabilities including:

- Acknowledging the difficulties of controlling biases that are unconscious and automatic. By examining our own biases and perceptions about disability we can avoid perpetuating stereotypes and misconceptions faced by people with disabilities.
- Self-monitoring: continuously self-monitor your perceptions, judgments, behavior, decisions, and actions for the influence of implicit biases.
- Accountability: hold yourself responsible for the negative influence that implicit biases have on your perceptions, judgments, behavior, decisions, and actions
- Learning and centering the experiences of people with disabilities. Getting to know people within the community and learning from their experience while engaging in positive meaningful relationships can help build new positive associations and reduce stereotyping.

Rehabilitation counselors should adopt the Disability-Related Counseling Competencies (DRCC) endorsed by the American Counseling Association (ACA) Governing Council in 2019. The purpose of the document is to encourage counselors to implement best practices, increase understanding, and assist people with disabilities (Chapin et al., 2018). With this in mind, rehabilitation counselors should seek to move beyond diagnosis and focus on quality of life to facilitate independence and autonomy. This is consistent with the belief that everyone should be supported in living life to their full potential. For

children with disabilities, it is vital for rehabilitation services to start as a child rather than waiting until adulthood. To achieve this, we must recognize the relationship among all areas of the child's life, including social, physical, emotional, cultural, and vocational aspects.

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