

ABSTRACT

A Parent's Role in Sibling Response to Intellectual Disability

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Growing up with an intellectually disabled sibling has distinct effects on a non-disabled child's development. Parenting these children while also parenting an intellectually disabled child is a uniquely stressful role. Using a grounded theory method, this research study explores the myriad of interconnected issues that affect parents' and children's response to having an intellectually disabled child in the family. Interviews were conducted with sixteen parents from nine families to better understand their perspectives on disability. In accordance with previous research, parental attitude toward disability was found to be a key factor in sibling adjustment. Parents' choices regarding education, delegation of responsibility, siblings' community involvement, and parent-child relationship also were shown to play a role in sibling response. In spite of the unique family stresses, parents interviewed indicated long-term positive impacts on their non-disabled children from growing up with a disabled sibling. The study summarizes significant factors of response to disability and implications for clinical and practical application.

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A PARENT'S ROLE IN SIBLING RESPONSE TO DISABILITY

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CHAPTER ONE

Introduction and Methods

Imagine being at the hospital after a child is born or at a routine check-up or in the hospital dealing with a child's illness or injury and hearing the doctor say that this child has a condition that is going to impair his or her ability to think and develop like the average child. There are a thousand questions racing through around the mind at once. Its unclear what kind of changes are going to take place in the home, and what this will mean for the future of a family. One may wonder what it means for a child to be labeled as "disabled" in the first place.

Intellectual disability, as defined by the National Institute of Child Health and Human Development, is a condition that begins anytime before a child turns eighteen that negatively affects ability to learn, reason, and problem solve, as well as causing problems with everyday life and social skills ("Intellectual and Developmental Disabilities (IDDs): Condition Information," n.d.). Disability has a broad spectrum of effects within a family, both positive and negative. As one father from this study stated, "There's no way your life can't change when you have a child with a disability. It automatically does by virtue of the fact that your child has a disability. And that's not bad; it just is" (F9¹). For typical² children growing up with an intellectually disabled brother or sister, researchers have found many possible negative affects of disability on one's life. The International Review of Research in Mental Retardation published a study saying that "Negative

¹ Parents will be referred to by their assigned case number and a letter (F for father and M for mother) throughout the study.

² The term "typical" is a commonly used descriptor in literature to refer to a non-disabled child

effects typically included anxiety, withdrawal, depression, somatization, acting-out behaviors, school problems, and lowered self-esteem” (Midlarsky, Hannah, Shvil, & Johnson, 2008, p 295). The very fact that having disability in a family makes the lifestyle in that home abnormal is in itself a trial for typical children. F7 described how "Home life is immediately disrupted because you're back and forth to the NICU. It disrupts your life with your older child who's shuttled to grandparents or left with one parent”

The negative effects on typical children in the family may fluctuate over time, and they may manifest themselves in different ways in different families. One study described the effects of disability on teens, saying that siblings of lower functioning individuals struggled with embarrassment and discomfort around their peers. With time, however, these feelings decreased (Davys, Mitchell, & Haigh, 2011). This type of short-term negative effect is to be expected in circumstances of such substantial change in home life, such as an intellectual disability. Beyond the short-term negative effects of disability on a typical child, however, some researchers have also found the overall experience of growing up with a disabled sibling to be a negative one, bringing about feelings of anxiety and depression (Sharpe & Rossiter, 2002). Siblings of children with disabilities have been described as disabled by association (Burke, 2004) This “chronic” negative impact is what many parents, caretakers, counselors, and researchers dealing with disability want to learn how to overcome.

Alternatively, however, researchers have also found short-term and long-term positive effects of growing up with an intellectually disabled brother or sister. According to Donald Meyer and Patricia Vadasy in their book on programs for siblings of special needs children entitled *Sibshops*, siblings of children with intellectual disabilities

demonstrate maturity, insight, tolerance, pride, loyalty, and compassion (Meyer & Vadasy, 1994). These children also often experience increased purpose, personal growth, and positive relations with others (Dykens, 2005).

Parents participating in the current study had additional insight on these positive effects: “95% of the time it's been a rewarding experience” M3 concluded about her autistic son. F9 described their family’s experience of having a daughter with Down Syndrome: “the joy that we have and the laughter that we have would be less without her.” Continuing, he said,

She forces us to keep moving forward. So we can't get stagnant or we can't stop trying to get better. And that's exhausting sometimes, but in the long run, it makes us a better family... We are way better off with her in our lives than without her in our lives, with a disability than without.

F2 described how growing up with an autistic brother had prepared his older daughter for motherhood. His son, also, had once called home after his epileptic wife had a major episode to say “I now know that God used [my disabled brother] in my life to help prepare me for the epilepsy.” These parents described how they could see the benefits of growing up with disability in the way that their typical children parented as adults.

Overall, there is significant controversy regarding whether or not growing up as a sibling of a disabled child is an overall positive or overall negative experience (Benderix & Sivberg, 2007; Benson & Karlof, 2008; Midlarsky et al., 2008; Seligman & Darling, 2007). Despite this disagreement in research, however, there are still children who are spending every day growing up in this reality. Knowing that there is such a wide spectrum of possible responses and outcomes for children with intellectually disabled siblings, the important next step would be to look into the biggest factors contributing to these sibling responses. Age, gender, birth order, family size, parental adjustment, family

climate, and level of disability have all been cited as factors to adjustment (Midlarsky et al., 2008). The current project found that parents' reactions and actions, as well as the support systems in place for parents, are one of the most significant factors contributing to a child's response to disability. The parent response, in conjunction with other factors, contributes powerfully to making the experience of growing up with a disabled sibling an overall positive one.

Grounded Theory

The research method used for this project is unique from other research methods typically utilized when completing a thesis. The method used is referred to as "Grounded Theory." Grounded theory has been used successfully in a variety of disciplines including nursing, computer science, psychology, and family studies; thus, grounded theory seemed to be the ideal research method to use in this project. While it is a research method that has been in use since 1967, when its pioneers Barney Glaser and Anselm Strauss published their work *The Discovery of Grounded Theory: Strategies for Qualitative Research* it can still be somewhat unfamiliar to researchers (Glaser, 2006). Grounded theory is more prevalent among social scientists than those involved in other branches of science (Bill Hoy, 2013). In 2006, the grounded theory approach became more commonly used in qualitative analysis than ethnography, phenomenology, and discourse analysis and narrative inquiry (Stern & Porr, 2011). That is not to say that these forms of research had not been useful in social sciences up until this point; in fact, phenomenology had laid groundwork for grounded theory as it had already rejected tradition scientific method approaches for use in the social sciences (Stern & Porr, 2011). Grounded theory, however, utilized additional methods to make the research even stronger.

As Glaser and Strauss defined in their groundbreaking first publication, grounded theory is “the discovery of theory from data systematically obtained from social research” (Glaser, 2006, p. 2). It is fundamentally different than the scientific method typically used in science theses. Instead of beginning with a defined thesis and attempting to prove this thesis correct or incorrect, grounded theory starts with a question and lets the research determine the final thesis. Because the social sciences do not typically deal with single-facet issues, it can be harder to simply prove or disprove a thesis. Often there are many other factors at play, factors that the researcher could not have known when originally formulating a thesis. The grounded theory method allows unanticipated factors to come to light during the research process. The researcher should be very familiar with the material before beginning a study, but research will not be compromised by this unanticipated information in the study. Assuming the researcher is thorough and attentive to the data that he is collecting, he will become well aware of any new information and how it fits in with the remainder of the thesis.

In order to “discover” the thesis and accommodate the complexity of the subject being studied, the grounded theorist begins with an initial framework in which he will conduct research. This is the unique standpoint from which the individual researcher approaches the problem, and it will provide direction for the progression of the research. Researchers may approach their projects from an intentionally feminist perspective, a certain political perspective, a psychological perspective, etc. This current project is somewhat framed by the concepts of nature and nurture. It is commonly accepted that children are impacted by both genetics and the environment in which they are raised (Myers, 2010). Both of these factors play a role in how children respond to having a

disabled sibling, so the focus of the research was to look more specifically at the role of nurturing in children's responses. Once establishing a framework, the researcher then lets the data emerge and guide the rest of the research process toward a final thesis. As Glaser and Strauss worded it, "generating a theory from the data means that most hypotheses and concepts not only come from the data, but are systematically worked out in relation to the data during the course of the research". Through a back-and-forth blend of interviewing, reading previously conducted research data, analysis of interviews, and studying published interview data, the researcher will gather information and relate what is in the literature to the new data he is gleaming. He will weed out what details are less important, and narrow the scope of the search toward the data that is surfacing.

This back-and-forth process is referred to as *constant comparison*. When the grounded theorist encounters one concept in an interview, he or she may return to the literature to do additional research in this area. When he notices that a certain concept continues to emerge from the literature, he may tailor the interview to gain more specific information about this topic. He may narrow or shift the target audience for interviewing based on the data that is emerging. For example, it became apparent during the first few interviews for this project that faith background seemed to be a significant factor in how families coped with the issue of disability. As a result, the target audience for interviews shifted towards families with a less significant religious affiliation in hopes that the effect of religion and faith would become more apparent. Had all of the interviews taken place without intermittent analysis and research, this factor could not have been as intentionally studied. Constant comparison is crucial in narrowing the scope of research toward a final thesis.

A result of constant comparison is that the literature review is not an independent chapter of the finished thesis document. Instead, the data that would be traditionally found in this chapter is woven into the other research data, providing a comprehensive analysis of previous and current research as they relate to one another. It is necessary that the researcher have a good basis of information before beginning research. The grounded theorist will study other research before beginning his own. Instead of leaving this research behind once he begins his own research, however, the grounded theorist continues to integrate older literature with the new research. “Academic literature,” say Phyllis Noerager Stern and Caroline Jane Porr in their book *Essentials of Accessible Grounded Theory*, “becomes data to be analyzed along with the interview, observational and documentary data” (Stern & Porr, 2011, p. 50). This mirrors the constant comparison that the researcher goes through, and it enables the reader to integrate all pieces of research into a comprehensive analysis. In grounded theory, the scientist’s current research is compared on the same ground as previous research, and they are placed side-by-side within the research paper. The researcher’s new data is valued just as highly as previously completed and published research (Stern & Porr, 2011).

As the grounded theorist organizes data during the constant comparison process, he utilizes methods referred to as “coding” and “memoing” (Stern & Porr, 2011). Much like how it sounds, coding involves taking the interview information and sorting it into related pieces. The researcher will break apart the interview information and identify specific themes that have emerged during the conversation. Repeated ideas will be simplified grouped into a shared category. For example, phrases such as “it’s always

been like this,” “this is normal for him,” and “she doesn’t know anything different” would be coded and grouped in the same category, referring to the idea that siblings of disabled children have an understanding of disability as typical reality. As the research process continues, the researcher will become more selective with this coding process, fewer and fewer themes will be coded for, and the most important themes will move to the forefront. According to Stern and Porr, “the grounded theorist strives to identify concepts and to create propositional statements connecting concepts, so that he or she can, eventually, weave them into a theoretical explanatory structure” (p. 42). The grounded theorist has the eventual goal of discovering one or a few main themes that emerge as the crux of the problem being researched.

Memoing occurs simultaneously as the researcher simply keeps record of all connections, new ideas, possible theses, and other thoughts that come up during an interview or research. Whether this takes the form of note-taking during an interview, typing up thoughts during a research session, or simply keeping a notebook on hand for spur-of-the-moment thoughts that come throughout the day, the grounded theory researcher can constantly absorb new information. These new questions and thoughts can then be melded in with the other information, and the thesis will begin to take a more defined shape. As stated in *The Discovery of Grounded Theory*, “A discovered, grounded theory...will tend to combine mostly concepts and hypotheses that have emerged from the data with some existing ones that are clearly useful” (Glaser, 2006, p. 46)

Unlike other forms of research, grounded theory does not shun bias of personal experience or outside influence. While bias can be dangerous if unchecked, the constant comparison of new information ensures that personal thoughts will not overtake other

research that has been done; personal experience is one source of information, but so are literature and interviewing. Research from all of these areas must be incorporated into the final thesis.

As the researcher does continue to put his or her own analyses into the research, Glaser and Strauss (2006) encourage the researcher to have what they call “theoretical sensitivity” in order to allow the true thesis to emerge from the data. The researcher should be constantly testing and questioning the thesis, aware of other possible theories, “whittling” his thesis to something reasonable and workable. Glaser and Strauss describe how theoretical sensitivity can be lost if the grounded theorist becomes too closely tied with one theory and refuses to consider other possible solutions to the problem being researched. As soon as the researcher stops allowing his theory to be questioned and reformed, the thesis is no longer emerging from the data. The final thesis must “fit” the data– the researcher should not squeeze the data into the thesis. It must also “work” in society; the thesis should accurately explain what was observed in the research as well as applying to real circumstances (p. 3).

The reason why grounded theory can be successful in real-life applications is because it is founded on the concepts of pragmatism and symbolic interactionism. In *Essentials of Grounded Theory*, Stern and Porr (2011) describe that “from a pragmatist perspective, debates over competing beliefs and ideas are worth the effort when they result in practical answers as to what to do next” (p. 28). In other words, grounded theory’s pragmatism emphasizes the importance of the applicability of a theory. Not only should the theory make sense with the data collected, but also the people from whom the data was collected should be able to agree with the theory that the researcher has

produced. If the data that the researcher sees emerging is truly grounded in the proposed theory, interview subjects should be able to agree with the theory. Stern and Porr encourage grounded theorists to constantly confirm with research participants that the emerging theory agrees with the participants' own experience.

Grounded theory was formulated to be useful in practical applications. While grounded theories should definitely be hypothetically useful, "prediction and explanation should be able to give the practitioner understanding and some control of situation" (Glaser, 2006, p. 3). Grounded theory is not just intended to produce a journal-like summary of the researcher's findings and observations; instead, the researcher must take the next step forward and produce some type of explanation for what was found. This theory is not a law, as with other scientific research; rather, it is a statement that is supported both by the emergent data from the researcher's findings as well as any previous research. This component of grounded theory research is what Stern and Porr refer to as "Explanation, not description." They describe how a grounded theorist extrapolates his or her research to a theoretical level. The observations and descriptions are necessary, but the researcher must go above mere description to draw additional, applicable conclusions.

Another component of pragmatism says that the data from a grounded theory study should be pertinent to greater contexts outside of that which is being directly studied. In the case of this study, it is hoped that the results from research done with a select group of families with intellectually disabled children will be further applicable to families in different social, economic, geographic, and political circumstances, dealing with a wider spectrum of disabilities. Although not every type of family structure can be

studied within the scope of this project, some of the theories produced from this research still have significance for other types of families. Grounded theory's basis of pragmatism forces its discoveries to bleed into real-life circumstances.

Additionally, symbolic interactionism is a key facet of grounded theory.

Symbolic interactionism can be compared to Watson's behaviorist perspective, Freud's psychoanalytic perspective, the functionalist perspective, the psychocultural perspective: it is another method of explaining human conduct (Stern & Porr, 2011). Symbolic interactionism says that an individual's actions are rooted in that person's interpretation of the symbols that surround him or her. Every person interprets symbols (objects, other people, virtues, institutions) differently. These interpretations change as the person interacts more with these symbols in his environment. For example, imagine a man coming upon a woman who is staring at a beautiful sunset and crying. If this man has only ever experienced crying in the context of sadness, he would assume that something about the sunset had caused the woman to be sad. If, however, the woman was crying tears of joy, this could expand the man's interpretation of tears to be something also associated with joy. Through the man's interaction with a symbol, crying, he has reacted in a particular manner. This specific social interaction has changed his interpretation of the symbol, and he will be enabled in the future to incorporate this information into his future symbolic interpretation. Grounded theory uses this idea of symbolic interactionism as it identifies how various participants react to certain symbols, explains the ramifications of these reactions, and applies these findings to broader circumstances. This project identifies how parents and siblings respond to disability, explains what the

results of these reactions are, and explains how these reactions impact each other as well as the broader community.

One characteristic about the methodology of this particular grounded theory project is the small pool from which the data is drawn. Sixteen participants were interviewed through the process of this project. While some research methods put emphasis on a higher quantitative value of research, the research in this study was emphasized for its quality. The information gleaned from a one hour, face-to-face interview provided a wealth of insight that could not have been gained from an informal paper survey. The validity of the data in a small-pool study like this comes from the grounded theory concept of data saturation. While each interview is unique, there comes a point at which the same themes emerge repeatedly. The coding process described earlier takes advantage of this concept. When the researcher begins to reach a breaking point in the data when few new concepts are emerging, he can be assured that he has gathered a significant enough amount of data that the thesis will be valuable and applicable in a variety of circumstances. While new information can always be discovered, saturated data is sufficient (Glaser, 2006).

Along with its implications and benefits for research within the social sciences specifically, the grounded theory research approach also seemed the best fit for me as a researcher. My personal inclination is to take notes when I think of them, write things down, compile information from different areas, and to integrate my thoughts and reasoning with a variety of other sources. This is essentially grounded theory. Memoing, constant comparison, and blending of research from a variety of sources come naturally; therefore, it seemed the ideal method of research in going about this project.

The goal of grounded theory, according to Stern and Porr (2011), is “to figure out what is important to people, what is problematic, and what is the process of events or action schemes implemented to achieve resolution” (p. 30). When described in this way, it becomes clear why grounded theory is such an ideal method for this specific project. The research seeks to find out what is most important to siblings and parents of intellectually disabled children, what causes problems in obtaining what is important, and what processes or actions can assist families in reaching these goals.

Participants and Procedure

After the research intents and methods were approved by the Baylor University Institutional Review Board, families from various areas in Minnesota and Texas were recruited to participate in a semi-structured interview to discuss the implications of having both intellectually disabled children as well as typical children. Only parents were interviewed; all participants were married, although both parents did not always participate in the interview process. All parents had at least one intellectually disabled child and at least one typical child. Parents were interviewed individually using the questions found in Appendix B as the basis for the interview. The interviewer could follow up with additional clarification questions when necessary, asking the participants to explain something they had said or to further expound upon answers they had given. This method, as opposed to doing a survey, allowed flexibility in the questions; thus, the interviewer was more able to explain the intent behind each question and to ensure understanding of the answers given. Furthermore, the conversation-like style of the interview process allowed parents the freedom to give complete answers and to expand beyond the bounds of the questions. This was particularly important given the grounded

theory foundation for this process; the flexibility of the interview meant that additional unforeseen factors of disability within a family could come to the surface even if they were not directly addressed in the initial questions. This allowed the researcher to expand the project's scope, not simply providing a yes or no conclusion to a hypothesis, but assessing the factors of disability that the researcher had foreseen alongside considerations that were brought to light by the families being interviewed.

The demographics for each family varied, with children's ages ranging from 1 year to 37 years of age. Additionally, the scope of disability varied greatly. While all disabilities included in this research were classified as intellectual disabilities, the scope of this definition is quite broad. This project included children with intellectual disabilities caused by autism, Down Syndrome, agenesis corpus callosum, traumatic brain injury, and other unspecified development disabilities of the brain. On one hand, including so many independent variables had the possibility of confounding the data. This inclusion produced difficulty in finding consistent results for factors that affect a sibling's response to disability as the type of disability and the needs of every family differed so much. However, including such a variety of subjects also seemed to have somewhat the opposite affect of confirming the factors that were discovered throughout the study. Although differing diagnoses changed the makeup of each family, the presence of certain common factors aiding sibling adjustment among all of the families confirmed the importance of these factors in any sibling's life, regardless of disability. The differences in diagnosis did have some impacts on sibling, the results of which will be discussed later.

Participants in the study were recruited using a modified snowball sampling method. Individuals who were previously aware of the project referred the first participants to the principal investigator. These families were then asked to give the researcher's contact information to other qualifying families who might be interested in participating. When these interested families contacted the researcher, they were informed about the purposes of the project and what the interview process would entail. If families were still interested in participating after they received this information, the interview was coordinated between the researcher and the family, and the participating parents read and signed the Informed Consent form, found in Appendix C. Interviews took place from November 2013 through January 2014.

Each individual interview was video recorded. After the initial interview, the researcher re-watched the video footage of the interview to take detailed notes, both of what had been said and what had been observed. Interviews were also watched a second time to create a partial transcript of the interview. These notes were then compared alongside other interview notes and previous literature, and they were analyzed for common themes or notable elements. As additional interviews were conducted and analyzed, these codes became more pronounced. Codes and research were continuously reanalyzed, and the sum of this data was compared and compiled into a final thesis as presented in this paper.

CHAPTER TWO

Parent Emotional Response

Parent attitude and the resulting family dynamics are arguably the largest contributing factor to a typical child's response to disability. Research from this study found that positive and supported parents are the best controllable asset that the sibling of a disabled child can have. According to other research cited by Kresak, Gallagher, & Rhodes (2009), a child's response to their sibling's disability can be strongly affected by their parents' attitudes about their brother or sister (p. 144). "The way that the stage is set early on can have a tremendous bearing on the life of the child with the disability and his or her siblings" remarked McMillan (2005, p. 351-352). The perspectives that parents choose to emphasize regarding their disabled child will impact whether their other children will have a positive or balanced point-of-view regarding their disabled sibling (Kresak et al., 2009). As such, one must first be aware of the impact of disability on parents, the experience of parenting both disabled and typical children, and the aids that best support these parents if they wish parents to be able to support their other children. If parents have a positive experience with disability, the typical children are more likely to have a positive experience as well.

Grieving

One of the most prevalent themes in talking with parents of disabled children was the idea of going through a grieving period after finding out that their child had a disability. "That was truly a time of real grieving for me," said M2. "Grieving to the

point where I didn't even want to have that neighbor bring over stuff on [disability-focused] school systems. I just wanted to pull in and grieve." Multiple parents cited common grief emotions that they worked through at different times following the diagnosis of their child. While the grief experience for parents of disabled children is not the same as experience of parents who experience the death of a child, parents described the grief of having a disabled child in this way. "You don't realize when you have a child, a healthy child, how many dreams you have attached to that child from the very, very beginning," M9 observed. But when her daughter was diagnosed with Down Syndrome, she began to think,

... is she ever gonna get married, and is she ever gonna go to school and is she ever gonna do this and is she ever gonna do that and are people gonna like her?... These hopes and dreams for your kids... when you have a child with a disability, it all just crashes.

M3 echoed a similar sentiment when describing her son's diagnosis of autism:

You're heartbroken because you have, I think every parent has this vision, of what their child will be like, and it's not that it's very specific, it's just oh my child's gonna grow up and they're gonna have friends and they're gonna go on dates and they're gonna go to college and they're gonna get married and have families on their own and careers, and your whole story changes.

For parents who have dreamed about what their child will be like or accomplish, a diagnosis of disability can be, in a way, the death of this child. Therefore, parents of disabled children often must grapple with these feelings of loss as they work through the absence of whom they thought or dreamed that their child would be.

As parents described their experiences of grief, there was a significant amount of variation in the manifestations of their grief, which is to be expected due to complex and unpredictable family responses (Seligman & Darling, 1999). Family 9 described the

grieving period as lasting less than a day before they had to begin working toward medical progress for their daughter's immediate heart problems:

We had our moment of sadness in the room, and then by 6 or 7 in the morning we wanted to start understanding from the doctors, and the cardiologists and the people that were over her care what are we going to do? Where are we going to go? How are we going to help this little girl stay alive? (F9)

The vast majority of parents described at least some extent of shock or denial at first: "I felt like I was coasting along in this airplane and all of a sudden it's starting to nosedive out of control," said M8. Remembers F2, "They said something about the baby having Down Syndrome or something like that and that hit us like a bolt of lightning," Said M6,

We didn't deal well with it at first. I mean, how do you deal with that? Being told that your child may not live...it was denial at first. I couldn't imagine him not being the way he was and sometimes I still can't imagine.

In multiple cases, parents took years to reconcile themselves with the reality of their child's disability. "There was almost a period of denial," described M8, "maybe until about the age of 2 or 3 of 'Maybe he's gonna grow out of this,' even though he had all these markers." M7 expressed a similar sentiment:

I really was hoping she wouldn't be as severe, I kept wanting her to be normal...It just made me so sad that I had this child that was going to have tons and tons and tons of struggles for her entire life...it took me a while to get beyond that.

She said it was close to a year before she felt like things were going to be okay. In another case, however, the parents didn't feel they had had to work through a feelings of denial: "It was such a gradual thing and it happened early enough that that hasn't really been a big shock or surprise or something that we've denied," said F1.

Denial can range from a hope for something different to a refusal to deal with the reality at hand, as M8 also expressed,

I grew up as a special needs sibling, so I was driving home from this appointment, and I was first of all looking back at my experience of growing up with siblings with special needs going 'I'm not going through that again!' I just had this bargain with God, 'I'm not doing it again!'

There can also strong feelings of anger, which F2 also identified with as he said, "'I think I was kind of mad at God for a while...[I was] asking the 'why me, why us?'...those kind of questions. And I think the extended family was asking the same questions.'"

"And then," said M7, "I went into full-fledged depression and misery over it. I kept thinking about all of the things that she would not be able to do." M1 described it as

...dealing with it, the day to day-ness of it, and just feeling like today was a bad day, and tomorrow will probably be a bad day, and the next day will probably be a bad day. It's not like this was one bad day. This is now my life. Forever. That's how it felt at the time, like it's just not going to get any better. And maybe it'll get worse.

Often these different emotional responses seemed to blend together, different emotions coming and going as parents worked through what their disabled child's life would look like. Anger could come at a time when the disabled child was having an especially difficult episode, as M8 describes her frustration, thinking "If he were typical, I could be at hockey practice with him right now," but instead, she was cleaning up her adolescent son's mess. Sadness can often return periodically when parents consider all of the parts of life in which the disabled child will never have the opportunity to take part. "I don't go there very often," said a M4, "grieving some of the things she doesn't have. Those are very sad places to go." She described how even as an adult, she still feels the loss on her disabled daughter's behalf of what she is unable to do, but she is glad that she can recognize this loss and not "make light" of her daughter's situation as some people do.

Embracing Disability

Working through these grief and loss emotions can be a back and forth process. Interestingly, this “back and forth” echoes a commonly held scholarly notion of the grief process known as the “dual process model” of grief. Dual Process asserts that in loss, individuals “oscillate between the loss focus of rumination and the hopefulness of restoration” (Stroebe & Schut). Parents described how some days were hopeful and other days were very difficult. There were many shared emotions, but different families experienced them at different times and to different extents. Even parents within the same family described how one parent grieved differently or coped with the disability in unique ways. As they worked through these emotions, however, parents in this study seemed to have come to or to be on their way to accepting the reality of disability in their lives.

Most parents had come to a point where they knew that this was the way their lives would be, and there was not a way around it. They had a sufficient understanding of the disability and what it might look like in their lives, and they had come to terms with this as their new reality, whether they want it to be that way or not.

With autism, it was so horrible at first, so painful...and then you get to a point where [you think] I might as well hop on this wagon and I might as well enjoy it because this is my life. (M3)

M7 reflected, "Now when I think about it, it really doesn't make me sad anymore. It is. It's a part of our lives." Said F9, “In order to make progress and move forward, you have to look ahead and not behind."

With some parents, as well, the attitude went beyond the scope of coming to terms with disability as life. This basic foundation of acceptance had been expanded as parents

were not resigned to the disability, but rather demonstrated desire to embrace their child's disability. When M7 began to accept and appreciate her daughter's disability, "...once I finally started to accept that...it's gonna be okay, we have a really good life and [my disabled daughter] is precious, I need to enjoy her... It got so much better. Once I started enjoying her for her." Similarly, multiple research studies cited in Van Riper's 2009 article described that passive and avoidant coping strategies such as wishful thinking have been linked with anxiety and depression, but according to Hastings, Allen, McDermott, and Still in 2002, positive thinking and reframing coping strategies were found to be beneficial. M9 described the outlook of her and her husband as, "We can be bitter or we can be better. It doesn't matter what it is, we could have a nonverbal autistic kid...We can still look at things as a blessing and see the accomplishments that that little boy or girl would have, and to help them get to where God wants them to be." Parents with these embracing tendencies seemed to have much more proactive and progressive goals, which served to benefit to the family as a whole.

Though moving past the thoughts of "Why is this happening to me? I don't want it to be this way!" often seemed the biggest hurdle for parents to overcome, talking with these parents provided evidence that this turning point is so important for families. This is not to say that there are no more periods of grief or that the parent has completely moved on- parents likely will continue to grieve much as bereft parents might as they think about a child's birthday or other milestones that have not been reached. However, parents likely will reach a point of accepting their life as a parent with a disabled child.

As one study described by Van Riper put it, coping with disability is a paradox in which parents experience and embrace both joy and sadness simultaneously (2007). This

study went on to describe that it is not only good but necessary for parents to embrace this paradox because “embracing the paradox energizes them and allows for hope, optimism, a positive vision of the future, and personal growth” (p. 118). Results of both acceptance and embracing disability were very clear in the results of this study. Upon reaching a basic level of acceptance, parents expressed a much greater level of comfort and ability to care for their other children. With acceptance of the disability came somewhat of a return to a sense of normalcy as life with the disability was viewed as “the new normal.” This idea of life as returning to normal meant that parents could continue involvement in their typical kids’ lives; they were able to coach sports teams, to participate in daily activities more freely, and otherwise be involved in the day-to-day aspects of their typical kids’ lives. Said M2, “If the kids had basketball, we all went to basketball. We all went to the North Shore. We just continued on with what we could do.”

Parents who had embraced disability were also more fully invested in finding resources to help their family. M7 described the feeling of “going through the motions,” learning what had to be learned about disability, but not truly being present until she began to embrace the disability for what it was, and for the potential her child could have. Parents who have looked beyond denial, regret, or anger that they have a disabled child are free instead to focus their energy on learning about their child’s disability, managing their specific child’s behavior, and learning how to unite all members of their family despite the disability.

Parents who embraced disability more completely exhibited more positive attitudes; for some families, this attitude transferred very powerfully to their typical

children as well. "Our goal is constantly that [our typical son] embrace those with disabilities, that he sees them not as different or broken or faulty...but to welcome and love them and to befriend them," said F7. His typical son, he describes, "has picked it up; he shares it. This is how we do life; he rolls with it. He sees [his disabled sister] as just as special and unique and wonderful as we do." Said F9, "We do the best we can not to treat [our disabled daughter] differently than a typical child would be. And so her sisters treat her that way too." The more complete level of acceptance was a precursor to the family integrating the disabled child fully into their daily lives. Practically speaking, this played out in an increase in whole-family activities and generally being more unified as a family unit. "We tried to keep the big kids and [our disabled son] as part of the same household" M2 explained. "We were all kind of in it together, trying to grow, trying to work our way through life with disability." "We were not a typical family," admitted M4, "but we tried to be. We went camping, we did everything we could." Parents expressed a shared desire to make as many activities possible as they could for the sake of all of their children.

"If we're all going to something like trick-or-treating, I feel like it's important that [our disabled daughter] go and I feel like it's important to [my typical son] too. I want him to grow up and see that she was just as involved in our family life. I want it to be where they're both just as involved as much as possible." (M7)

M8 described their household rule: "We're doing dinner together, whether it's 5 in the evening or 8, we're all doing it together to get that family time." One study found that 12 of 20 families were encouraged by the parents to engage in shared activities with all members of the family to manage the changes in routine, and to foster time together (Schneider, Wood, Llewellyn, & McConnell, 2006). This attitude of integration is

something that can be encouraged by any involved medical staff and supporting community as well. M9 remembered,

The doctors kept telling us 'Just take her home, she's a baby, just love on her. Love your child and do everything you would for her as if she was a typical child and she will flourish and she will grow.

Parents who spoke of integrated activities also seemed to express a positive reaction in their children, they commonly described close relationships with their typical children, which are of high importance for these children. Previous research affirms the conclusion that there is “greater positive affect in the sibling relationship where more shared activities took place” (Davys et al., 2011). Similarly, research done by faculty at the University of Massachusetts found that family climate, including parent and child participation in shared family activities, was a significant predictor in pro-social behavior of children in non-diagnosed siblings (Benson & Karlof, 2008).

Integration could also be played out in more ways than physical activities. Attitudes of inclusion can also foster a sense of sibling pride. Siblings who see their parents embracing their siblings’ disability seemed more likely to express the same attitudes of acceptance, as the previously cited articles by Kresak and McMillan alluded to. Parents in this study clearly reported that siblings took pride in their brother or sister’s unique personality and abilities.

She's his sister that he's proud of; he's constantly telling people about her, everyone at his school knows about [our disabled daughter] from [our typical son]. They think she's great because that's what they've heard from him. He reflects and leads the way in our attitudes. (F7)

This son’s mother went on to describe how she had walked in on her son playing a few days before: “I came in and it looked like he was playing the board game Sorry by himself.” Upon asking him about it, her son replied, “No, I'm playing with [my sister]

and she's winning!" Continued his mother later in the interview, "he gets that [his disabled sister] is special and different, but he still wants her to be involved." F4 began describing a similar closeness and inclusion in the relationship between his daughter with a brain abnormality and her typical sister. "They would share the same room," he said. "They had bunk beds and all the stuffed animals were on one level and they would share a bed on the other level." He had tears forming in his eyes as he described how the older typical daughter would wake her younger disabled sister up just so they could snuggle together and she could say goodnight.

Communicating with the disabled child in a different way or changing the manner in which the disabled child was talked about among family members and friends was also expressed as a way to make life more normal for typical children. "We don't talk to her like she has a disability, we just talk to her," said M7 of her family's interaction with their nonverbal daughter. F9 gave the reminder that,

Every child is different and you have circumstances that come up and you handle them differently because of who the child is and their personality, but that's how we handle her differently as well, it's not because she has a disability. We know she can't do certain things or she's gonna be slower at different things, or whatever, but we just treat that as part of who she is, not saying 'Oh, that's Down Syndrome'. That's [our daughter]. She'll get there when she gets there.

F1 had the same sentiment when describing his autistic son:

[My typical son and my autistic son] are different and have different needs. It's the recognition that you can't always expect the same thing from them and you can't always discipline them the same way. So maybe, in that sense, whether it's because of the autism or because he's goofy or whatever the reasons are, I think [it's about] just recognizing that there are differences between them and treating them differently when it's appropriate.

Disability aside, parents can recognize that there are inevitably going to be differences between their children, and many of the differences in how they treat their children are

going to be a result of personality differences in their children. In a similar manner, parents also recognize that their disabled child is still just as much their son or daughter. Said F7 of his daughter, “She's gonna be my little girl, pure and simple, and she's perfect as any daughter is for any daddy.”

One of the key components of a parent’s embracing the disability is the positive attitude that comes along with this perspective. According to one article, “the parents with better well-being and who can maintain a more positive mental health status may be better able to better cope with stressful demands of caregiving” (Gerstein, Crnic, Blacher, & Baker, 2009) These parents did not view disability as an unfair problem they had to manage and provide care for, and therefore did not communicate this type of attitude to their typical children. Rather, these parents viewed the disability as a part of their lives that they were going to make the most of. Other literature is in agreement with this finding, as one article encourages the use of affirming communication style that “conveys support and caring, and exerts a calming influence” (Van Riper, 2007, p. 125).

Typical children seemed to pick up on this attitude whenever it was present. “We focus on her. I don't focus on what she can't do; I focus on her and what she can do,” said M7. She went on to describe her typical son’s similar attitude: He'll introduce her to his friends and he'll say “This is my baby sister and she can't chew or she can't walk but she can play and she laughs! Listen to her laugh.” M9 said that “from the very beginning... in the way that we've talked about [our daughter with Down Syndrome], she's just always been a blessing and she's always been a special gift, and so I don't feel like there has been any negative feelings or any jealousy issues.” She continued by saying, “her sisters, they both set the example that [their disabled sister] is really cool to hang with.”

Factors Affecting and Encouraging the Embracing of Disability

Seeing the obvious benefits for parents, siblings, and the family unit as a whole of embracing disability and integrating the disabled child into the family, researchers should look for what affects and aids parents as they seek these perspectives. Personality was one important factor in parental acceptance. As the Van Riper study (2007) described for families of children with Down Syndrome, it is essential for caretakers to recognize the natural resilience that families with disability are capable of; doubts of these parents' natural abilities to cope and reconcile with disability can impair this resiliency or impede a positive relationship between parents and caretakers. Particularly when looking at data from sets of couples, it became clear that sometimes one parent was more accepting of, or positive about, disability than the other. Comparison between parents in the same family made other factors equal, making it more apparent that some parents simply had a more positive tendency than others. Comparing data between parents even allowed one to see some differences between husbands and wives in their acceptance of disability.

In some cases, the progression was about the same. In many instances, however, it was harder for one parent to come to terms with disability than the other. Sometimes the wife expressed having a more difficult time adjusting to disability because she was the parent who spent most of the time at home, continually being reminded of the differences that disability brought. "I'm in the trenches here," described M3, a stay-at-home-mom. Agreed M2, "Moms are here, we have our hands on the situation and dads, they have to go off." Admitting the difference between herself and her husband, one mother said, "I definitely had a harder time with it than [my husband] did. He accepted it really well. It just took me a while to catch up to that." However, other couples

expressed that wives were more able than their husbands to reconcile themselves with the disability.

Interestingly, previous experience with disability did not appear to play a role in parental embracing of disability. Parents in this study ranged from no previous experience with any type of disability to growing up with a disabled sibling. It did not appear that parents without previous experience with disability were at any disadvantage in coming to terms with disability. Even parents who had previous disability experience did not express any quicker of an adjustment, although once they had accepted the disability they seemed to make some parenting decisions based upon previous experience. M7, the mother who had grown up with a disabled brother, believed that she had certain considerations in the time that she spent with her typical son, although her coming to terms with disability did not seem to differ from the other parents in the study. There was not a significant amount of previous research on parent response to disability as it relates to previous experience, so additional research in this area specifically would be beneficial.

Embracing disability is also very affected by the type of disability. Parents agreed overall in their desire to have both a diagnosis and a prognosis. Said M7,

It was really important to me to know what she had. I just really wanted a diagnosis. I would spend hours on the computer searching, and that would make me even more depressed... think I would've done better without the Internet.

Her husband agreed with this struggle as he detailed the difficulty of having no idea how long their undiagnosed child would live, if she would outlive her parents, etc. "We've since accepted [not having a diagnosis] and are fine with that, but when you don't know, I

think that was hardest because you don't know what's coming, you can't plan." M6 described her experience of waiting and how difficult it was as doctors tried to provide a reasonable prediction for the medical future of their disabled son: "They could never tell us what to expect and if they did, it was always the worst." In confirmation, recent literature has quoted "time lapse between suspicion and diagnosis" as a stressor that affects the parental response to disability (Bingham, Correa, & Huber, 2012).

Parents in the current study expressed how much they appreciated having an expectation for their child's behavior and future. Disabilities that are more common or well understood may have a more defined prognosis. As a result, sometimes parents can have an easier time adjusting when they know what they need to expect.

The blessing about Down Syndrome is that it is what it is. You have a blood test and it is this disability, where some families don't even want to admit that there's something wrong, much less have to fight for your child to say 'There is something wrong and we need help.' (M9)

F9 agreed, saying "For us, it was black and white, she had that extra chromosome. That made it very simple in that regard, to just knowing 'this is what we're up against' whereas other disabilities that's a lot harder." F1 described his experiences, saying "We get the sense that a lot of parents are terrified of it or don't want a label. We wanted a label because we knew there'd be help that came with it." He continued on to describe how it helped just knowing that it was something other people had experienced before.

It helped to make sense of things, although it certainly opened up another pathway that I hadn't considered going forward. I was relieved just to have more of a definitive idea of what was going on, even if we weren't sure where to go from here.

His wife had similar feeling about their diagnosis: "It was good in that it gave me a direction to go as far as private services."

However, sometimes the patterns and behaviors associated with a disability do not progress as anticipated. "We had always said 'He has the developmental delays, but thank God he's not a behavior problem,' " said M1, "and he started having significant meltdowns all over the place." His father described that, "It kept snowballing to the point of almost being impossible to manage. In school, he was basically isolated or couldn't participate at the same level he was even weeks or months before that at school." Although they had been expecting developmental delays to continue in one way, the disability manifested itself in a different manner than was initially anticipated. Inability to predict outcomes has been found by other researchers to affect parental reactions (Bingham et al., 2012).

The autism spectrum, along with many other diagnosis categories, is quite vast and encompasses a wide range of prognoses under one general diagnosis. This can make it very difficult for parents of disabled children to come to terms with what they're dealing with. As M4 described her experience after getting a specific diagnosis of Agenesis Corpus Callosum, "Diagnosis does not equal the disability. [For our daughter,] there's more abnormal "something" in the brain, but we haven't gone any further with that. It would be only knowledge, it wouldn't change things." Even if there is a technical name for a child's disability, the disease will often change or progress in unexpected ways; it is impossible to know exactly how an intellectual disability will develop and, as a result, difficult to accept the future. In the end, predicting outcomes of intellectual disabilities is difficult, and it is just that: prediction. M9 seemed to echo what the mothers in the Bingham study said:

With every other medical diagnosis, there's a severity of it. With any kind of disability, you can't give a percentage of how bad it is. I just wanted to brace myself for how bad it was going to be, and nobody could tell me that. I would say that probably took us a month, two months, to get past that...

For many parents, this “unknown” may not be something they feel they can “get over” very soon.

One struggle that families with both known and unknown diagnoses faced was the pressure of improvement for their child. Having a more defined prognosis was somewhat of a detriment to some families. Because the progression of the disease had been studied more, it was accompanied by greater familiarity and greater expectation for certain developments in a child with that specific disability. Parents expressed the feeling, either for themselves or for families that they knew, that they had to do enough of various therapies to get their child to reach a certain milestone. F7 described how, despite the difficulty of not knowing what her diagnosis was, he felt there was less pressure to achieve with an unknown prognosis. Interestingly, it is also possible for parents of children with unknown disabilities to feel that urgency for their child to be at the best position possible: "It put a lot of pressure on us to try to do everything we could to help [our disabled daughter]" said M5. She talked of how she and her husband “spent all waking time doing therapy to get her to the best possible position.”

Social unacceptability of the disease can make it much harder for parents who feel as though they are ostracized or alone because of their child’s behavior. "It's just harder to function in normal social circumstances. Even just outings to the grocery store or going to Target... it's a challenge,” said M8. M3 cited the benefit of having a diagnosis in in difficult social circumstances, saying that if they went to someone’s house, “...and he starts walking across the countertops...now you know why." Other parents may not

know of anyone else who has a child with the same disease as their child. An isolated parent, as a result, can tend to have a longer period before he or she accepts a child's disability. Literature agrees that behavior problems increase parenting stress levels (Spratt, Saylor, & Macias, 2007). Another study found that delays in social skills most consistently predicted higher levels of parenting stress (Davis & Carter, 2008).

Furthermore, not only does "maladaptive child behavior" increase a parent's stress level, but higher parenting stress will, in turn, worsen the child's behavior (Baker, McIntyre, Blacher, & Crnic, 2003). These points once again emphasize the necessity of support for parents.

Additionally, diseases can be more challenging to adjust to when they are accompanied by some of the more difficult symptoms such as violence. Said M2, "[The period of violence] was very, very difficult for us as a family. We were walking on eggshells a lot." According to one study, behavioral problems associated with an intellectual disability increase the level of challenge to the family (Baker et al., 2003). M7 had a difficult time accepting the disability because her newborn daughter did not act toward her how a newborn typically would. "It was just hard in general because she was just very stiff, very irritable, very hard to hold." These behavioral differences can make it so much harder for parents to accept a "new normal."

Timing of diagnosis is another major factor in parent response. For many parents, diagnosis may happen immediately at birth, so planning for the future and changes within the home start to happen immediately. For other parents, they may begin to notice behavior changes months or years into childhood development, and the diagnosis can take months after the initial changes are seen. In some cases, adjustment is already

taking place, so the actual diagnosis can come as a final push or confirmation to accept the child's future and move forward. For other families, the diagnosis may not come until much later. Mothers in other studies have described frustration with medical staff at having to wait for months to receive definitive answers as to what the diagnosis was, whereas the faster diagnoses seemed to be tied to more positive mother-provider relationships (Bingham et al., 2012). M6, whose son became disabled in his teens said, "Even though I know what the reality is now, sometimes it is still almost like you wake up and think, 'this can't be.' " There is a possibility that disabilities that do not occur or become apparent until later in the child's life are more difficult for a family to adjust to, which would align with the findings of the Bingham study. These findings are suggestive of the importance of research into diagnostic techniques for disability.

One of the factors that emerged through the study as a major contributor to parental acceptance and embracing of disability, especially amidst these unknowns, was the presence of a religious faith. It seemed quite plausible given the interview data from this research that there was a connection between the presence of a practicing religious belief the extent to which parents accepted and embraced disability. Much of this seemed to be based on a strong conviction in God's plan and sovereignty, both for the disabled child and for the family as a whole. When asked what helped her to cope the most with her son's disability, M1 replied,

The firm belief that God made [our son] this way and he's supposed to be this way. A lot of people have a hard time accepting it or are hoping to change it or cure it or fix it and that's not where we are at all.

M4 answered that, "the disability came as a total surprise, but we know that God is in that and he holds our lives in his hands. It wasn't an accident; it was more about God's very

personal plan for us.” Similarly, F2 put forth his belief that,

it wasn't just a bunch of chromosomes that got together in a haphazard way, in a mindless design less fashion. [My faith] helped me to see that God has a plan, and it's not only for [my disabled son]'s good, but it's for my good too.

Different parents reiterated the same sentiment that they could not imagine having a child with a disability and not having a faith in God as well.

My faith has meant everything through this. That we could cling to something about God's providence even in the darkest hardest points when you're wondering what's happened and why it's happened. I actually don't know how people do it without faith.

In particular, these parents stressed the importance of knowing that the life of their child was purposefully created by God. Parents described how faith provided a reason behind disability: "Things don't just happen, they happen with purpose,” F2 stated. “Learning to look at [my son]'s disability through the eyes of faith helped a lot.” As F9 put it,

Having a faith in God and in Christ Jesus is a complete game changer. It gives us knowledge of a purpose for each life, and we know [our daughter] was created and designed specifically by God, for a purpose, so we try to live that out every day. She wasn't a mistake, she wasn't an accident.

In one 2012 study, all six participating mothers in a study about responses to a disability diagnosis expressed the helpfulness in seeking spiritual support in order to cope (Bingham et al., 2012). These findings relate to an earlier finding that personal faith, even more than the actual religious institution, were viewed as an incredibly important support (Long et al., 2013). In the current study, faith played a key role in helping families to navigate the emotions of grief, as well as helping families to accept disability. It was a source of strength and hope for parents dealing with sadness; "I don't know how anyone can go through this and not have a relationship with the Lord,” said the M6,

whose son suffered a traumatic brain injury. She continued:

That's the only thing that's sustained me, because if you don't have that, you don't have hope. Hope comes from having peace and having joy, not joy in your circumstances or having that happy feeling, but joy in being thankful for things, for what you do have, and joy in knowing that this is not the end, that I have something much better to look forward...if I didn't have that, I'd just be in despair all the time.

This idea of hope was confirmed in one study, which found hope to be a protective factor for parents, combating the possible negative outcomes for caregivers of intellectually disabled children (Cooke, 2010). According to interviews, it also seemed that this trust in God sometimes carried over to their children's view of disability as well.

Also on the topic of faith and disability, M9 said, "There is a saying that God will never give you more than you can handle- and that is so not true. God does give you more than you can handle, it's just that he will give you the strength to be able to get through it. And he has this "body of Christ"³ that is meant to be there to help support you." As she and many other parents expressed, another key contributor in the acceptance of disability was the emotional support of family, or other such support from a community. Similarly, one 2002 study concluded that "the helpfulness of informal social support resources were helpful to mothers in developing a sense of personal growth and maturity" (Hastings et al., 2002).

Among a plethora of other benefits that these communities of people offered, parents expressed that the emotional support of family and friends to help them to accept the disability. Describing a fellow mother of an autistic child, M1 remembered, "[She] was on my speed dial when we first got the diagnosis. I would just get totally overwhelmed and I'd call her and be like 'I don't know what I'm supposed to do right

³ This term is commonly used in Christianity to refer to the community of those that hold the same beliefs.

now." M3 stated her belief that, "People are our best gift to each other. The most isolated thing in the world is people that don't have support systems." "It's without doubt community and friendship that make all the difference," said the F7 of his experience with parents dealing with disability. "[Parents dealing with disability] cannot feel cut off and too many do, and we have not had that experience and it's made it entirely different for us." His wife remembered the feeling of being alone at first as she was dealing with her daughter's disability:

None of my friends have a child with this significant of a disability... So when I was able to read blogs on the internet of people who, you know, they're just like us, a regular old couple that had another child... and then they had a child with a disability... and I'm like 'oh they're like us.' So that really helped me

As she described, this emotional community support could come from a across the street or across the state. Whatever the source, however, the support was just as important in adjusting, according to these families. Said F3, "You're not alone in it, so there's something just that realization helped a lot."

At the same time, however, it is important to note that close communities did not always necessarily offer this type of support. Just as emotionally supportive families were a means to acceptance, emotionally difficult families often added to the burden of stress felt by parents in coming to terms with disability. Parents have reported in the past that informal support outside of the family was lacking, so families often had to rely on more formal support systems (Schneider et al., 2006).

Within the current study, immediate and extended family were sometimes cited as the most difficult group of people to deal with. "Even among disability, no experience is the same. We have our own unique challenges that no one can understand, even family can't understand it often," F7 said. Offering unwanted advice or otherwise downplaying

the impact of disability was often an incredibly difficult roadblock for parents to get over in order to accept their disabled child's condition. F2 remembered hearing comments like "Oh, this didn't come from our side of the family." M4 began, "Some of the stupidest things that you can imagine being said will come from your immediate family." She continued, "My mom and dad have always been very supportive of us, but they're not a support system with our needs for [our disabled daughter]. They don't get it." She said that lowering her expectations of family helped her to cope:

Family can be really strange. We don't put a lot of expectations on people... We kind of know that some people will embrace it and some people will act awkward with it. We don't have any expectation [with those outside the family], but with family we tend to.

The same difficulty could be encountered as typical children grew older and began families, as family 2 experienced. These children distanced significantly from their immediate family for a short time after leaving for college. As their mom remembered, "It seemed like the spouses were kind of egging our kids on and we kind of wondered if maybe it didn't ramp up more than it had to."

In addition to offering emotional support, family and friends can also offer tangible support to families dealing with disability. Once the initial diagnosis is made, there are a spectrum of changes and responsibilities being added to a parent's life. As M1 described,

Once they give you the diagnosis, they have this laundry list of suggestions: Do this therapy, do that therapy... There are only so many hours in a day and so many days in a week. Where do you go? Who do you talk to? Who do you call? That was all very, very overwhelming for a few months.

Whether or not the parents are emotionally prepared or supported through this change, they must also be physically and financially prepared. Multiple studies cited by

Baker, McIntyre, Blacher, and Crnic in 2003 found that adding a disability to a family will inevitably increase the demands on the family. Emotional support of family and friends has an impact on a parent's ability to accept their child's disability, but of equal importance is the tangible support that these communities can offer. Palpable resources were described to be helpful in coping with the changes of disability. Parents repeatedly expressed the necessity for a community around them to provide service, time, financial support, or another means of aiding parents in shouldering additional commitments.

Van Riper's 2007 article urged nursing staff to promote family adaptation by encouraging use of community resources because research had found these resources to be helpful. "People could really come alongside us and really carry us when we needed help with meals and with visits and with love," remembers F9. M9 added, "These strangers who didn't know us reached out to us in ways that we weren't expecting. That was a cool part of starting that walk with disability ministry." "We don't feel lost in the system," M8 said. "We feel like if we have a need, we know where to go and who to talk to." F8 described how he and his wife are currently going through the process of regaining custody of their disabled son as he turns 18. "We have people that have gone through that ahead of us in our support system, which is a real comfort in that regard."

Having family nearby, while being cited as an important resource by the Van Riper study, was also one of the commonly cited concrete resources for parents:

I know what helped us tremendously is that we have two grandmas, [my husband's] mom and my mom, that would come and stay for a 6-week period of time or a 3-week period of time. When we had large hospital stays, they would come for that hospital stay. (M9)

Not only was this a relief for this mother, who was commuting back and forth from the hospital, but it was an important relationship for her other children: "When they were

little, they loved it because I was gone all the time, but they had grandma." M7 expressed with like appreciation the impact it had to have his family close as their family was trying to deal with their additional time constraints:

Our extended families were amazing... [they] helped pick up the slack. [Our typical son] still talks about this one time when [his disabled sister] was in the hospital...when he got to go spend 4 nights with my parents.

For families who may not have the immediate time-support of extended family or in-laws, other communities can step in to provide the necessary support. These communities can supplement the time and energy that parents dealing with a new diagnosis might not have. Benson and Karlof cited multiple sources to describe the vulnerability of typical children with autistic siblings to family difficulties as caregiving stresses can magnify conflict between parents in the home (2008).

The ability of surrounding communities and family to, in a way, multiply a parent's time and take some of the caregiving stresses off of their shoulders can help to pacify some of the conflict that these children may be so sensitive to. According to White & Hastings' 2004 study, "Parents' ratings of the helpfulness of informal sources of support (spouse, extended family, friends, etc.) were most reliably associated with parental well-being, and remained so after controlling for child characteristics" (p. 181). In fact, this study found that the tangible, practice support of a community was found to be helpful to families dealing with severe intellectual disabilities while emotional support was not.

More specifically than just family or community, many parents in the current study expressed gratitude for the unique support that other families dealing with disability offered. Not only did these other families understand what it was like to go through the

diagnosis and adjustment of disability, but they also had additional insight into outside resources available for families with disabilities. These additional resources can be like buried treasure for parents coping with disability; "It wasn't until [my disabled daughter] was 2 that someone said, 'You don't have a case manager with the county? Wow, there's all these resources that you could have!' ” said M9. She described how a case manager was able to get them financial help as well as a waiver for respite care so staff could come into the house a few times per week to care for their daughter. “If we didn't have that kind of support from her waiver, it would be different.” According to research done by Jansen, van der Putten, and Vlaskamp in 2013 found that professional support centered around the family was important, but a significant percentage of parents did not feel that they received this support. Taking the time to research this information or go to support groups takes time that many families might not feel they have. This also runs contrary to the White and Hastings study, which found that only social support was of great importance while professional support was not.

The financial burdens of disability can be very overwhelming at first also, as F2 described as he talked about the changes within their family’s home:

Everything you do centers around paying for that. We led a pretty happy lifestyle, got fairly impulsive sometimes if we wanted to be...and all of a sudden we got tied down in ways that we hadn't ever been tied down before...[Our disabled son] represented a lot of costs.

According to one study, developmental disability can bring about economic difficult in families, especially considering the study’s further finding that mothers with disabled children have reduced rates of employment (Parish, Seltzer, Greenberg, & Floyd, 2004). Looking to Benefits.gov, a government-run website that provides the public with information regarding eligibility for certain benefits and grants, there are a variety of

grants available to provide aid to families with disability. These include funding for diagnostic testing, coordination of care, and development of an Individualized Education Plan (“Disability assistance,” n.d.). These resources can be a tool to help parents cope as well as an aid to parents who have accepted their child’s disability and wish to find ways to progress in caring for their disabled child and their family as a whole.

The implications of this part of the research are far-reaching. As communities become aware of families with special needs among them, it is essential that these communities recognize the part they play in assisting these parents to adjust to their new lifestyle. Community assistance enables parents to see and respond to the diverse needs of all of their children, as M5 clearly expressed: "Both girls need different parenting styles...That's a concern is knowing how to meet the needs for [our typical daughter] when we're doing all this extra stuff for [our disabled daughter]." This support enables parents to be more equipped to handle the new struggles that accompany disability. This conclusion is supported by a recent study showing that in families with disability,

Interventions aimed at helping parents to manage stress, improve parenting skills, strengthen family communication and problem-solving skills, as well as maintain family routines may be useful. Strengthening sibling, parent, and overall family functioning may also improve family members ability to cope with and meet the needs of the person with a disability. (Goudie, Havercamp, Jamieson, & Sahr, 2013, p. 481)

Whether providing care, emotional support, perpetual bonds of friendship, financial support, assistance in caring for other children, or any other means of helping, these parents are greatly impacted by the support of their community. It strengthens them physically, emotionally, mentally, and spiritually. As a result, these parents will be more capable of being better parents to all of their children, as will be discussed in more detail.

Any support offered to a parent of a disabled child is indirectly a support to the typical children in that family.

CHAPTER THREE

Parental Actions

The perspectives and attitudes of parents are major contributing factors for a child's response to having an intellectually disabled sibling, but there are other factors beyond parent's attitude and coping that can influence a child's reaction. A parent's active responses to a child's disability, their actions in relationships, and their choices regarding their typical children's lives are some of the largest factors impacting typical children.

Marriage

When considering disability and its effects on the family, marriage is one of the major topics of discussion. According to Kennedy Krieger Institute, an institution that works specifically with families dealing with pediatric developmentally disability, many people believe the "80% statistic," which says that 80% of couples with an autistic children get a divorce (Lustig, Megan, 2010). Many families in this study described similar concerns that disability can take a toll on a marriage and eventually break it apart. M8 described how she has seen in so many parents pouring themselves into trying to find a cure for their child because they want to alleviate the stress and difficulty of the situation. "I think that's what breaks up a lot of marriages," she said, "because they're so focused on the child that they lose track of the spouse." Due to the added stress and responsibilities of disability, parents found themselves tending to get frustrated and angry more quickly than usual.

It was like every ounce of patience I had went to [my disabled son] and I was really good at that. I have seemingly an unlimited supply of patience with him. But then it all comes out sideways and everyone else, including [my other son] and [my husband].

Other parents described having much shorter tempers and tending to take it out on their spouse.

Contrary to the “80%” however, the Kennedy Krieger Institute found divorce rates in families affected by autism to be the same as that of typical families.

Additionally, marriage was more often referred to throughout this study as a necessity rather than a relationship in need of repair. “Not that [disability] didn’t rock our marriage,” said M1, but she stated “having a solid partner” as one of the biggest aids to coping with disability. With five of the six couples that were interviewed in the present study, at least one if not both of the parents cited that a supportive spouse or strong marriage had helped themselves or their children significantly in dealing with disability. According to previous research, marital quality was found to be predictive of the parent’s wellbeing (Kersh, Hedvat, Hauser-Cram, & Warfield, 2006). M9 stated earnestly,

I can paint a rosy picture of what our life is like with [our disabled daughter] and how great it is– and it is great– but it would be very different if I didn’t have a husband that supported me.

It is an interesting paradox to consider, that though coping with disability requires so much strength in a marriage, it has great potential to place immense strain on the relationship.

It seemed particularly important for the women in the study that they have a supportive husband. Mothers reiterated the role their husbands had played as support systems for them and as involved fathers for their children. They appreciated the presence of their husbands to provide care as well as emotional support. “I can’t imagine

being a single parent and doing this or being in a marriage where the spouse is not involved or doesn't want to help.” said M7 “We have relied on each other so much throughout this time.” These assertions are further bolstered by research that found that even though mothers experience increasing daily parenting stress compared to fathers, this stress can be prevented by positively perceptions of marital adjustment (Gerstein et al., 2009).

Additionally, parents can be a resource for each other in that the parent that spends more time at home with the disabled child can educate the other parent on how to best deal with the disability. As F1 put it, his wife was “doing the homework.” As one study found, however, it is not necessarily the amount of support that helps a parent, but rather the type of support. The support parents offer to each other must be “in tune,” each parent receiving the type of support that helps him or her the most effectively (Bristol, Gallagher, & Schopler, 1988).

Not only do strong marriages provide substantial support for the parents themselves, but it is has also been proven to be an important factor in child adjustment. According to one early study, “the relationship between the parents appears to be psychologically transmitted to the well-being of the parent and the care of the child” (Bristol et al., 1988). A strong marriage can provide instrumental support given study findings that say siblings of some disabled children are more susceptible to impacts of experiencing family stress, such as divorce (Nixon & Cummings, 1999). Furthermore, other studies have found that positive family relationships, strong marriages, and lower levels of parent conflict can influence the child’s pro-social behavior and behavior for the positive (Benson & Karlof, 2008). From a personal perspective, one father stated that the

best help for his typical son was, “staying together, knowing that a child's security depends so much on the parents just staying together.” Strengthening a marriage strengthens the individual parents, as well as strengthening the family. Marriage support offered to a parent is part of the framework that supports typical children.

Parent Education

The level of a parent’s education regarding disability has been shown in multiple cases to have an impact on the family as a whole as well as the siblings in particular. Benson and Karlof (2008) speculated that a parent’s educational involvement may enable him or her to meet the needs of their disabled child better, which would reduce overall family stress as a result. Additionally, increased education about a child’s disability can facilitate a stronger parent relationship with their disabled child; according to research compiled in by Midlarsky et al. (2008), positive relationships between parents and their disabled children indicated better sibling-sibling relationships, while negative and limited interactions between parents and disabled children can be associated with negative relationship effects between typical and disabled siblings. When describing some of his disabled son’s atypical behavior, F8 described that the reason his autistic son kept jumping from the top of their stairs was to get sensory stimulation. He understood his son’s disability in a way that enabled him to understand that his son was not necessarily being intentionally deviant, but that there was reasoning behind his behavior. Similarly, F1 said,

The biggest thing is just adjusting to what's a reasonable expectation. ...I finally realized [my disabled son] just doesn't get it. He's not being willfully bad or willfully ignoring us, he just doesn't understand what we asked him to do.

Said his wife, “[My husband and I] had to completely change how we think about parenting. How we parent [our typical son] is completely different than how we parent [our disabled son].”

M1 went on to describe how understanding of an intellectually disabled child’s behavior can then be passed on to his or her siblings. One of the biggest aids for her typical son was “knowing that [his disabled brother] is different, and there's a reason for it. Reinforcing that when [his brother] blows up at him that he handled the situation correctly.” Kresak et. al (2009) found that being open with siblings in talking about their disabled brother or sister can lessen possible negative effects of disability. M5 had a similar goal in educating her typical daughter, saying that she and her husband make an effort to make sure that their typical daughter understands why her disabled sister has some of the behaviors that she has. This mother said it was difficult for her daughter to understand some of the double standards in discipline, because some of the means of discipline and expectations that her parents have of her are different than those that they place on her disabled sister. However, she is beginning to understand the ‘why’ behind it more as she gets older. Furthermore, parent education has been shown to improve pro-social behavior and decrease total difficulties in siblings of disabled children (Benson & Karlof, 2008).

In addition to the positive impacts of education described by this literature, parents in the current study showed that this improved understanding in their typical children consequently helped them to be proud of their siblings and to act more as advocates on their behalf. M9 talked about how she made a point to go into each of her kids’ classrooms at school to explain Down Syndrome to their peers. As for her typical

daughters, "They know what it is and they have no shame. ...If somebody were to reject [their disabled sister], I think they'd be more angry at their being ignorant than for them to feel bad themselves." Her involvement and understanding of disability seems to have served as an aid to her children in responding to potential difficulties of disability. M5 gave practical examples of how her daughter's understanding of the implications of disability. "If I show frustration or anger at [my disabled daughter]," she said, "[my typical daughter] will say 'Mom, you know she can't help it.' She's a great defender; she's never hit [her sister] back. She can be more consistent with [her sister] than the rest of us can."

There is some debate as to the level of education children should receive regarding their disabled siblings. As one researcher stated, "It is important to remember that siblings' need for information will change as siblings age and develop and that they will need to periodically receive information throughout their lives" (Kresak et al., 2009). As M2 remembers about her typical kids' education and adjustment,

Early on, the kids were real accepting. I think they had all the information about Down Syndrome that they ever wanted to know. It was just matter-of-fact conversations, I don't remember [official sit-down conversations] being a real big part because we had this living scenario happening. It wasn't like we were trying to educate them about the neighbor's children, [their disabled brother] was right here.

Education should be tailored to what is desired and necessary for the child, trying to find a balance between under-educating and over-educating. Despite the discrepancies in amount education necessary for each individual child, however, some level of parental involvement in their disabled child's therapy and education can indicate the adjustment of their typical children.

Independence and the Parent-Child Relationship

When parents and children are both educated regarding the disability and “on the same page,” it can be much easier to facilitate activities and care within a family. Sibling education is a means to family unity. One resource for parents entitled *Nobody’s Perfect*, encourages parents to have weekly meetings to encourage families to all understand the plan of action in taking care of a disabled member of the family (Miller, 1994). While some families said they had come together at one point to have a more formal discussion about the changes that were taking place as a result of disability, this sort of official meeting did not appear to have had any major impact on the typical child’s overall response. Most of the families in the current study described a sort of ongoing education for their children. Though they did not have an official meeting, they addressed questions their typical children had as they came up in conversation. In general, the manner in which children were educated about disability seemed to be much less important than the fact that they were being included in the conversation in the first place.

One benefit to having more official conversations, as mentioned in Miller, is that parents continue to recognize the needs of their other children, their willingness and helpfulness as well as their need for independence. This independence relates to a typical child’s own space as well as the child’s responsibility within the family. Most parents in some way acknowledged their typical children’s need to have their own lives and their own physical space. M8, who had grown up with a disabled sibling herself, expressed a significant amount of concern that her son be able to have his own space. "There was a period where we had to lock the door on [our typical son’s] room to keep [our autistic

son] out.” She remembered from personal experience, “My brother would damage some of my stuff and I would get really angry about that.”

Many families were also intentional about enrolling their children in different school systems in order to maintain both independent physical space and another community for their typical child. According to research, disabled siblings could often be a source of teasing or embarrassment for older siblings; having children in separate schools is a good way to prevent that (Davys et al., 2011). M1 wanted to enroll her typical son in a different school system to avoid these potential situations:

He doesn't have to worry about...walking around the corner in the hall one day and seeing his brother freaking out on the floor in the hall. It's completely separate, no one's gonna know. Not that he's ashamed of it, he's not, but he just doesn't have to deal with it at school. School is just his.

M3 wanted to avoid the possibility of additional responsibility being assigned away from the home on account of her daughters' disabled brother. “Any teacher they had seemed to want to pair them off with other autistic children,” M3 recalled. “[My typical daughter] shouldn't have to be the one always dealing with it.” These families wanted their children to have a separate place, somewhere that could be their own. Even when one family did eventually enroll their two sons in the same school system, they were cautious to ensure that their typical child was okay with this change.

Within the home as well, providing space was important to parents. F1 emphasized the importance to him and his wife of allowing their typical son to have some time away from his disabled brother:

[Our typical son] starting to get to the point where [his disabled brother] is kind of cramping his style a little bit, so we're doing our best to not just stick it on him but we can deal with the tantrum for 5 or 10 minutes while he leaves and [our disabled son] stays home.

Research in other literature also found separate physical space to be used as a coping strategy by the family (Schneider et al., 2006). M8 gave the example of allowing their typical son to have space when his brother's disability became uncomfortable: "[Our disabled son] had a really bad seizure and [our typical son] got really uncomfortable with that and said 'I'm gonna go out and ride my bike!'...He just needed to escape from that situation."

In addition to physical space, a child's individual activities and life were an important factor in adjustment. Setting aside time for typical children while accounting for all of the disabled child needs was one of the most difficult aspects of disability, but not having this time could lead to resentment among typical children. Said M2 of her typical children,

I think that there was some anger at God for taking mom and dad away. We didn't have the time for them, we didn't have the money like we used to. It changed life in our household. I think they were mad at us for that.

Children with disabled siblings may believe that their parents care less for them than for their disabled brother or sister, whether or not this is actually accurate (Seligman & Darling, 2007). M3 said that ninety percent of her time was spent with her autistic son when he was at home with their family. "[Our typical daughter's] memory is that we hardly spent any time with her...She probably got the backseat to him a lot." Agreed F3, "When he lived here, he just kind of consumed all your attention. He was always the focus." Parents may focus the majority of their attention on the child with the disability because of that child's level of need, which can leave typically developing children feeling neglected, as Seligman and Darling found (2007). Parents often seemed to have an understanding of this possibility, whether by intuition or through experience. M9 said,

I have a friend who's daughter hated her little brother, and basically it was because of all the attention he was getting and she didn't get very much. We did try as much as we could when [our children] were little to take the kids individually out on dates or just do something with the kids that it wasn't always about [our disabled daughter].

Parents expressed a strong desire to make time specifically for their older children because they believed it to be helpful to typical sibling adjustment. M4 explained, "We had recognition that we had to balance [our disabled daughter] with our other children. Life couldn't be all about her. We had an immediate balancing awareness." Research shows that if children with intellectually disabled siblings believe themselves to be treated less favorably by their parents, they are more likely to express negative emotions, and they are more likely to have difficulty adjusting (Dunn, Stocker, & Plomin, 1990).

Often parents tried to make activities as fair as possible for their other children. F7, in talking about his disabled daughter, described how, "We've tried to be very careful that everything not revolve just around [her]. She's one other family member. Even if she has her special needs and things that demand time...there's also always stuff for [our son]." By involving their children in sports, music lessons, school trips, and other activities, parents expressed an effort to provide opportunities for their other children. F8 expressed the priority of "making sure that [our typical son] has as many opportunities available for him to be a normal teenager. I didn't want him to feel like he was missing out because of [disability]." These opportunities can ensure the typical child that he or she is still an important priority to his or her parents, even in spite of the other time commitments that a disabled sibling may require.

Other parents described ways of trying to get individual time with each of their children. "We keep [our typical son] up until 8:30 or 9 by design. He gets that time

where there's not the stress... It's just mommy and daddy" said M1. F8 talked about how he and his typical son have a shared love of sports that brings just the two of them together "Football season has always been a good time for us" he laughed. Given the difficulty of finding this time to spend together, other parents said they took advantage of everything from coaching sports teams to helping in school classrooms to making a point to talk during car rides in order to maximize time with their typical children. Outside support was also very important in facilitating this time. Whether through care of extended family, a disability support group, or government aid to provide in-home care, these resources seemed very much appreciated by parents as a means to important individual time with their typical children.

Having these individual activities can help typical children to feel equally important as their sibling, strengthening the parent-child relationship. "I worried that disability would negatively affect my relationship with [my typical son]" said M7, "but maybe it's been a positive thing because I've tried to make that conscious effort," she said. According to the literature cited by Gerstein et al. (2009), "a positive parent-child relationship has consistently been shown to be associated with positive child outcomes in typically developing children as well as children with intellectual disabilities." Responses from parents in the current study indicated that they found stronger parent-child relationships to be helpful to their children's adjustment; said M1 of her typical son, "He's really at that age where he really identifies with dad and I think getting along with his dad as much as possible has been a big help." Parent-child relationships were shown to be beneficial to the parents as well; a positive father-child relationship reduced the

burden of daily tasks on the mother and overall daily parenting stress can be predicted by parent-child relationships (Gerstein et al., 2009).

In some cases, it took moving the disabled child to a different home to ensure that typical children had the home life that they needed. Although this is not an option that all families may want to consider, this could be one way to best provide both necessary space as well as safety for all members of the family. M3 described how changes took place in their lives after the placement of their son in a group home: “We finally made the decision to do more things together. We hadn't eaten out in years.” Another family talked about the benefits of moving their disabled adult child to a group home, which allowed the parents to spend more time with their adult children and grandchildren.

Another aspect of this parent-child relationship was the level of vulnerability and general communication that parents had with typical children. It can be difficult to maintain a strong relationship amidst the stress, which showed as M1 remembered her son asking her “How come we don't get along, Mommy? Why are you so mad at me all the time?” She cited one of the biggest aids to her typical son’s adjustment was “admitting when I've screwed up”. She described how she wanted to remind her son that she was stressed and apologize for taking that out on him, “in the hopes that he's not gonna internalize it and that he's gonna know that when I do get short with him that I know that I'm wrong and that he's not a bad kid.” Interestingly, research affirms that a maternal relationship specifically is linked to a higher likelihood of caregiving in typical children (Davys et al., 2011). This research was confirmed in the caring behavior of the son in the family described above. Other research cited by Midlarsky et al. has also

confirmed the importance of communication in lessening anxiety in typical siblings (2008).

Having individual activities is not only a means for a stronger parent-child relationship, but it also provides a community for the typical child. Just as parents cited the benefits of having their own community to rely on while coping with disability, typical children also benefit from having their own community. In some cases, this took the shape of the child's sports teams, in others just friends near home or at school. One brother found his community in being able to spend time away at his neighbor's house. His mom, M1, explained how the neighbors also knew their disabled son and understood how he functioned. "[Our typical son] is over there all the time. That's hard for me, but very, very good for him, so it's fine...Just that he has a place to go has been a huge help for him." M2 and M4 both described the tendency of their older daughters to separate from the family when they got married- having another community with their spouse or in-laws was a place to be on their own, separated from the demands of disability for a little while. Especially for older children, they may tend to maintain involvement in the communities where they were already tied before the having a sibling with a disability in order to maintain some continuity and normalcy during a time of so much change in adjusting to disability.

Community sometimes took the shape of a group specifically engineered toward children with disabled siblings. Don Meyer pioneered one system cognizant of special needs called Sibshops. In his book written with Patricia Vadasay, their research encouraged giving the same attention and respect to typical children as to their parents when considering counseling services (Meyer & Vadasay, 1994). According to research

cited by Sharpe and Rossiter, “Information sessions and support groups have been shown to enhance children’s psychological state, their knowledge of disabilities, and their understanding of the family situation” (2002, p. 707). Similarly, Benderix and Sivberg urged that counseling services and peer support groups should be available to children with disabled siblings (2007). While M8 said that their typical son didn’t seem to have a need for a special-needs-specific support group, some other families described that their children had benefitted from the Sibshops program, or from another special-needs-specific program. On the other hand, M6 noted worry for her oldest son that he had never quite gotten over the disability of his younger brother because he had never gotten enough of a chance to talk about it. Some typical children may not express a need to talk with counselors or others with disabled siblings while some will; what is important is that the resource is available in case the child does need to have a community with which to talk.

Sibling Responsibility

Another benefit when parents encourage discussion and openness within a family is that it enables siblings to be involved in the plan of care, makes them feel important, and ensures them that they have some say in the matters that affect them so closely (1994). The conversation regarding a child’s responsibility in taking care of his or her disabled sibling can be a difficult one that has many implications for a child’s life and attitudes. According one 2009 article, parents or other providers should ask siblings of disabled children the extent to which they want to be included in care (Kresak et al.). Because of the fact that the typical children tend to be the ones who are closest to and

spend the most time with the disabled sibling, they can be incredibly helpful and supportive if they want to be involved.

In so many families, one of the most significant questions is how much responsibility to delegate to typical children in the care of the disabled child. As noted, there is a significant addition of responsibility to a family when they have a child with an intellectual disability. To be fair, there is going to be an additional responsibility when any child is added to a family, whether or not this child has an intellectual disability.

Observed F9:

When [our disabled child] came home, in some ways that point was like any child coming home: it transforms the dynamic you go from one child to two children and that's the adjustment already that takes place, just learning to add this new person.

However, the additional demands placed on a family when dealing with issues such as feeding, dressing, and otherwise caring for an intellectually disabled child are significant. There is high likelihood that parents will rely, to some extent, on their other children to assist in the care of their intellectually disabled child. According to Jeanne Safer's book, children with intellectually disabled siblings have double the responsibility of children without disabled siblings because they feel have to make up for their siblings' deficits as well as fulfilling their parents expectations of themselves (2003). According to another study, sisters in particular are regarded as caregivers across the child's lifespan (Orsmond, G. & Seltzer, M. M., 2000). One study cited by Davys et al. (2011) said that sometimes children may even act out of a desire to exceed what their parents have done to take care of their disabled siblings and provide for them in repayment for the life they have not had.

In agreement with this information, parents seemed very careful in delegating responsibility to their typical children; they did not want to place an undue burden on these other children. “We were in charge and not them,” said M3 of her other children. “They weren't responsible for taking care of him. I never saw that as their role to do.” F8 said he and his wife didn’t want to put their typical son in charge of caregiving because he needed to be able to take care of himself first before he could provide for someone else.

However, that is not to say that families expect no help from their other children. One study looked at independent child activities as well as the interdependent role of caretaking activities that some siblings had and found in particular that “need to balance independence and interdependence opportunities for children without disabilities was an important family dynamic emerging during [the] adolescent phase” (Schneider, Wood, Llewellyn, & McConnell, 2006, p. 929). Parents expressed that their children were expected and willing to help, especially when they understood the implications of their contributions to helping the family to function. “The family system that we have works because we all work together. We all are pulling or we're always doing something to make it work,” said M9. Furthermore, research cites that this kind of “helping” behavior can actually be very beneficial to the typical child. According to a study done in 2008, children who are assigned helping responsibilities are more likely to engage in helping behavior and those children that were engaged in helping reported significantly higher levels of self-esteem and happiness than those that did not (Midlarsky et al., 2008). Instead of negatively affecting a child’s daily functioning and activities, the responsibility was actually a benefit to them. According to the study, these children were also more

likely to be generous. Even cross-culturally, children naturally tended to be helping in the support of their siblings. In cases of children with disabled siblings, “the siblings of children with mental retardation were found to provide more custodial care and emotional support than siblings of children with no developmental disability” (p. 307).

In addition to setting appropriate boundaries and expectation for caregiving, parents also set an important example in the way that they take care of their disabled child. Helpful children tend to have parents who are classified as more caring, compassionate, and empathetic (Midlarsky et al., 2008). Another study found that children tend to “exhibit higher self-efficacy” if their mother modeled empathy, care, and responsibility (Grissom and Borkowsky, as cited in Midlarsky et al., 2008).

Alternatively, M5 remarked that her typical daughter has also picked up on negative responses; “When I’m at my wits end, not knowing what to do with [my disabled daughter], [my typical daughter] will act in a similar way as I do at times.”

According to parents, many of their children exhibited natural caretaking tendency toward their siblings. “[My typical daughter] would always help me with the feeding tube feedings. [My typical children] were always involved in her care,” M9 described. Said M1, “All babies should come with an 8-year-old sibling. ...He’ll be the first one to go and get something.” F1 added,

He's kind of like the mom or grandma that worries 'Oh, he's gonna get hurt!' which is somewhat nice because he's protective of him when they're playing outside, half-watching and making sure he's not doing something he's not supposed to do or crossing the street on his own, things like that.

Some parents expressed that they did, as the Kresak research suggested, assign responsibility to their typical children only on an “as-wanted” basis. Described M4,

We gave [our middle daughter] responsibility because she wanted it. With [our older daughter], we didn't give her as much responsibility because we didn't know how connected she'd be with [her disabled sister]...She was older and a little more advanced with seeking her own friends and her own things. It was more about their energy than anything that we directed.

Said F7 of his son and his disabled sister, "He is wholly and completely gentle with her, tender, caring, he includes her with everything, we've never taught him that, we've never told him to do that, it's wholly him."

CHAPTER FOUR

Uncontrollable Factors

While there are many aspects of disability and family life that can be controlled and changed, there are also many parts of disability and its effects on the family that are uncontrolled variables. These are interesting and important factors to consider precisely because of the fact that they cannot be changed; because of these unchangeable variables, awareness of the controllable variables are all the more important.

Personality

In a broader application of a child's natural caretaking tendencies, a child's personality as a whole has significant impact on the response to disability. While parental impacts are valid and the weight of a parent's attitude, education, and delegation should be taken into account, it is of equal importance to remember the child's personality in the face of disability. F9 described how the individual interactions between his two typical daughters and their sister with Down Syndrome were very different. "[The middle daughter and our disabled daughter are playmates, and they play together a lot.... That's more [the middle's] style, that's her personality, she wants to play and do things and be active."

For family 4, the mother expressed how her typical daughter's personality was just as much, if not more of a determinant than disability of the environment within their home as they raised their three children. "Our firstborn was very strong-willed and at many times in bringing up our children, she was the hardest one, not [our disabled

daughter]. The strong will and stubborn spirit of a child often had much more of our attention." When describing her two boys' response to the disability of their third, M6, "If either of them were to be adversely affected, it would be the older because of his personality." In each of these three families, the child's personality was singled out as a major component of this child's response. Despite safeguards put in place to protect a typical child's independence, parental positivity, counseling or support systems, or anticipation for a negative response, it is ultimately the decision of the typical child as to how he or she is going to respond the differences in having a disabled brother or sister.

Type of Disability.

One of the most obvious unchangeable aspects of disability is the type of disability. On one hand, some studies have found type of disability to have no effect on a child's response. According to repeated studies, severity of the disabled child's disability does not affect the functional level of the typical siblings (Davys et al. 2002; Sharpe & Rossiter, 2011). Other research and the information from this study, however, beg to differ.

Like a parent's response, a children's response to disability will be deeply rooted in the type of disability present because of the resulting changes it brings. As mentioned earlier, intellectual disability in general adds tensions to a family's life. According to one study conducted by Sharpe and Rossiter in 2002, "Families experiencing childhood chronic illness must adapt to caregiving burdens, stress, and anxiety demands" (p. 707). Depending on the disability, these caregiving burdens and the consequential negative effects can vary in severity. According this same study, siblings of children with disabilities that require more intense, day-to-day care are affected more significantly than

siblings requiring less care; the study said that this is partly due to the parental attention required when a disability is more intense. According to one parent in the current study,

We knew they were growing up in a family that was quite different than those down the block. Families that are affected by disability do live different lives... You spend lots and lots of time going to therapies, doctors appointments. There are tensions in the home that some families don't know anything about.
(M2)

As a result of his daughter's disability, F7 recalls being awake for 20 to 22 hours each day when she was first diagnosed. "You're not getting sleep, so it's hard and its stressful, which adds a lot of stress to anything you do in the home," he said. Other parents agreed that stress levels are higher and patience levels are lower with a disabled child in the family, leading to more conflict. As cited previously, siblings of disabled children tend to be much more sensitive to these tensions and stressors, so a more demanding disability could lead to additional strain on placed on the typical child or children.

Another component of the effect of differing disabilities is directly related to the fact that the increased caregiving required of parents means that they simply do not have enough time as they would have otherwise. Thus, the necessary support in the parent-child relationship, as discussed above, suffers as a result. "Parents of typically developing children have, in general, more time and resources to seek help for children with significant functional impairment than do parents raising a child with disability" affirms Goudie's 2013 study (p. 481). The increase in care has a snowball effect: The parents must provide a greater level of care, inhibiting them from spending the same amount of time building their relationship with their other children, which can cause the other children to either feel bitter and neglected (as previously discussed) or to take on additional responsibility out of compulsion. M3 remembered her older daughter

complaining to her that she and her husband loved their disabled child more. "There's just some things that we don't do as a family and I don't know if we ever will," said M9.

She later added,

There's always that adaptation of 'Well, we can't stay or we have to take different cars because I know she has to be in bed by a certain time and if she doesn't then she's laying on the floor and then she's crying...'

Families express the use of a home health nurse or other in-home care to be helpful in maximizing free time in the home. Knowledge of government resources can be particularly useful. In some cases, parents pay their typical children, who are very familiar with their sibling's disability, as caretakers. This allows them to be involved, but also gives a sense of responsibility and control in the matter.

Ability to communicate normally can be another of the major barriers between siblings that changes depending on the severity or type of disability. For some siblings, this may not be a problem. For example, some children with Down Syndrome or a higher functional level of autism may still be verbal and capable of carrying out a somewhat typical conversation with their siblings. M9 described that with their daughter with Down Syndrome, "the more she grows, there's more interaction and there's more ability to interact because [our disabled daughter's] vocabulary is bigger and she can be understood more by her big sisters." In other cases, however, the disabled child may have little to no ability to communicate. In these circumstances, siblings must find other means of communication and interaction. Sometimes, they can develop their own means of communication and interaction. "They play together in their own way," said M7 of her typical son and disabled daughter. "He throws the ball to her and he'll go to the other side and throw it back over." She said that he knows all the ways he can make her laugh.

In other circumstances, particularly when the typical child is older than their disabled sibling, it can be hard to grasp this inability to have a normal relationship. As M1 talked about her two sons' communication and interaction, she described the impact it had on her typical son when her disabled son did not speak to him as would typically be appropriate. Describing her disabled son, she said, "Hurt feelings are meaningless to him. [To him,] we all think the same way, have the same brain and same thought process." These differences can make relationship formation vastly different than it would be otherwise. She described the difficulties of abnormal sibling interactions for her typical son, saying "It's hard for him that he has a brother so close in age that doesn't play... [Our disabled son] doesn't play *with*, he plays *next to*, so they can't play a game together...It's frustrating and it's stressful. [Our typical son] is pretty compassionate- he understands, I think, but he likes breaks."

As one article described, siblings can find a space forming in their relationship with their disabled brother or sister as their interests and abilities become increasingly divergent (Schneider et al., 2006). M6 described her son as grieving the loss of the typical relationship he had enjoyed with his younger brother before the younger boy became disabled. "It's been hard for him to lose that kind of buddy that he had...They still can play video games together like they did before, but it's not the same because [my older son] has to help [my younger disabled son] hold the controller, and he probably misses that." Along with the changes that a disability brings for the disabled child's social interactions and thought processes, the typical child's daily life is affected as a result of the change in relationship.

As the previous discussion alludes to, changes in a child's thought process not only have an effect on communication and language, but also on daily functionality. Just as is the case with a disabled sibling's ability to speak and interact within the family, other aspects of the disabled child's functional level can have an impact on the relationship. It looks much different for a child to have a relationship with a disabled sibling who is active than one who is less mobile or wheelchair-bound. Greater adaptability in the disabled child has been proven to be an advantage to families (Corrice & Glidden, 2009). Additionally, some typical children have simply adapted to having a sibling who they know is unable to do certain things. Typical children in the current study had often questioned these differences at some point, but with the "in-the-moment education" that many typical siblings receive as they are growing up with a disabled sibling, children often become accustomed to this reality. "This is the only brother that's been able to talk to him and truly play with, so he doesn't know anything different from a brother-to-brother relationship," F1. It can be much more difficult for typical children who were older when their disabled sibling was born or whose siblings became disabled later.

Along with the personal difficulty that siblings face in forming a modified relationship with a disabled sibling or the time constraints brought about by a sibling's daily care requirements, typical children also face the dynamic of public approval for their siblings' disabilities. In some cases, disability can be much more socially acceptable. F9 described that "because of [our disabled daughter's] engaging personality and how fun she is and how happy she is and how cute she is, literally everyone is attracted to her and she gets attention from most people in a good way." A study done by

Freeman and Kasari in 1998 utilized multiple other sources to describe the easygoing, endearing nature that children with Down Syndrome can have that facilitates social comfort and formation of relationships. On the other hand, some disabilities might not be perceived as positively. Autism, for example, can be difficult because of its tendency to make children seem more removed (Freeman & Kasari, 1998). Even different cases of Down Syndrome can elicit different responses from others as the personality does not always follow the endearing nature that Freeman and Kasari cited. Furthermore, disability may not be immediately apparent to an onlooker. This can make going out into public places difficult for families some families because other people may not understand why their disabled child is acting differently. M3 had shirts made for her son that said “Autistic and Proud of It” for her disabled son to give others an idea of why he might be acting strangely. For typical siblings, it can be difficult to deal with public embarrassment of a sibling that might cause disturbances or act in a strange way around their friends, Some parents discussed the possibility of friends not wanting to come over as a result of disability, and research described children’s tendency to not want friends to come to their home if the child with disability was present (Benderix & Sivberg, 2007). Interestingly, however, other parents also cited their typical children as being the strongest advocates for their children in the face any judgment.

Violence

Beyond just acting out in public, some disabilities have the added dimension of physical violence. Having a sibling who frequently exhibits violent behavior is not only a major public disturbance, but it is also a factor within the home. Some of the typical children in the families of this study had experienced difficulty forming meaningful

relationships with their disabled children because they were targets of their siblings' violent behavior. M5 said her disabled daughter is currently in a stage where she throws things when she wants attention, so often the older girl doesn't want to have anything to do with her at that point.

For the two sisters in family 3 with an autistic brother between them in age, it was difficult to form a relationship because he had always taken out his violent behavior on them. "That kind of behavior has kept them from having a close, tight relationship with him and wanting to be around him," said their mother, "because who wants to get hurt?" More than public embarrassment, violence has direct impact on the sibling-sibling relationship. As research has described, the unpredictability of violence can cause anxiety for typical children (Benderix & Sivberg, 2007). For a boy in family 1, it was difficult to know what behavior to expect from his disabled brother and how to respond to it: "Sometimes [our disabled son] takes it well and has fun and they wrestle around like any brothers would, and sometimes if [he's] not in the mood, he gets violent and pushes him or punches [our typical son]...That hurts [our typical son's] feelings because he knows he didn't do anything wrong, he's just trying to help."

Violent behavior is not always a constant factor, but often will become worse during certain life stages. The mere increase in a child's size can make him or her much more difficult to discipline, leaving parents feeling out of control (Schneider et al., 2006). As M2 put it, "It's one thing to have a little guy swinging his fists and kicking, but it's another thing when they get to be bigger. The violence was hard on all of us." For this family, getting appropriate medical care made the difference in dealing with their Down Syndrome child's violence:

We had several years of ebbing and flowing. Things would get really stirred up, and it was basically because the meds weren't right. We all knew when the meds were right, and what that did for us. It gave us time to breathe.

Although his medicine did not completely eliminate the violent behavior, it helped enough to tame the violence to a more manageable level. In some cases, violence associated with disability can be enough to necessitate changes within the home. Violent behavior can leave typical children feeling unsafe in their own home, and some siblings have been cited to express the desire for their disabled sibling to be moved outside of the home in order to bring relief (Benderix & Sivberg, 2007). M3 described the difficulty she faced when her son's violent behavior was directed at her typical daughter: "On the one hand I'm his mother, but I'm her mother too. At that moment, he's not my son; he's somebody attacking my child." This family decided that, for their well-being, it would be better if their son was moved into a facility that was better equipped with protective safeguards to deal with his size and behavior. Parent-child relationships were described to have improved as a result of this move. Violent behavior, more than other factors, seemed to be resistant to outside support because it is not necessarily something that community aid can have as significant of an impact to alleviate. Out of all the factors affecting child response to disability, it seems that finding ways to aid families dealing with violence and disability aids the most additional research.

Age, Gender, and Number of Children

When thinking about changes from disability, one must also keep in mind that having a disabled sibling is often the norm for many typical children. Though research provides mixed information regarding the effect of birth order on sibling adjustment (Surratt, 2008), the current research seemed to say that the adjustment was easier for

children who have had a disabled sibling since they were young. They don't know life any differently; they have lived their own disability education. Parent after parent described how this was their typical children's normal life it always had been. Like growing up in a family that speaks another language, living with their siblings' disabilities has been integrated into their daily life. They may respond positively or negatively, but the recognition of what life with a disabled sibling is like will come inevitably.

M7 described how she was thankful that her typical son was young enough at the birth of their disabled daughter that he didn't really remember much of a change at that time. "[Our disabled daughter] has always been there as far back as he can remember and so it's just been a very natural thing for him. He accepted it the best out of all of us." Her husband described how accustomed their son was to disability: "We've watched him walk the house...carrying a bicycle pump. And he gets out a baby doll... and he puts the pump right up to her belly and goes 'I'm feeding the baby.'" M3 gave the example of her daughter telling her mom that her Barbie had autism.

These children have benefitted from a constant education on disability from the time they were young enough to begin learning. Often children who have been closer in age seem to have become accustomed to disability as a normal and inevitable change; it appears they have a good understanding of why certain ground rules are in place, as M1 described:

There's a lot of things that don't make sense, why if we're in the car and [our typical son] is eating and he has to have cheese and bread, he can't have crackers because the chewing's too loud. And that's the stuff he handles really well. He doesn't get upset about that stuff. Because he's seen the meltdowns and he knows it's not worth it...He's really good about that kind of stuff.

Unlike parents and older siblings who must go through a phase of adjustment and acceptance, siblings who are closer in age to the disabled child and who never knew life without this disability have much of the need for adjustment taken off of their shoulders.

That is not to say that it is not still a difficult transition for kids closer in age, or that older children who experienced transition to disability cannot have a positive relationship or that children who have grown up with disability will always have a positive experience. In fact, research cited by Surratt (2008) has found increased age between siblings to be associated with better sibling adjustment. It is, however, a much different process for older children who may have more of a tendency to grieve the loss of what their lives or siblings' lives were like prior to disability (Benderix & Sivberg, 2007)

For older children, relationship transitions with parents and typical children can still be relatively smooth. "I was the mom," said M2. "I was continuing to cook and wash and do stuff at school... I don't really know that there really was that much of a relationship change." Sibling-sibling relationships can also still be positive, as F9 described the "true older-younger sister relationship" that his typical and disabled daughter had. "[Our older daughter] is the cool big sister and [our younger disabled daughter] loves hanging out with her and her friends and being part of that dynamic." However, older children do tend to respond differently to disability due to the necessity to adjust. Older siblings have been cited as having greater coping and behavior difficulties (Macks & Reeve, 2007). An older brother in family 2, aged 11 at the time of his brother's diagnosis, was described by his parents as being more removed. At this point, he already had his own life, and he tended to gravitate more towards the activities

he was already involved in rather than caring for his brother. This is not necessarily a positive or negative, but it is a good example of the tendency of older typical children to not have as close of a relationship with their younger disabled brother or sister. F2 also described how the son younger than their disabled child didn't "suffer the same neglect" as the older children, because he required additional baby care at first, then just blended into the normal family routine.

In family 9, parents described their oldest daughter to be very motherly to their Down Syndrome daughter, whereas the child closer in age treated her as a peer. For family 4, the older sister, who was 6 at the time of the diagnosis, grew up being very distant from her disabled sister while the middle sister, aged 3 at the time of diagnosis, had a very close relationship with her disabled sister that has persisted through childhood and into adulthood. Overall through the current study, older children seemed to have a more variable response throughout childhood and adolescence to adding a disabled sibling to the family, whereas younger children seemed to have more consistent response during the developmental years. According to other research, there is no confirmation whether or not differences in age have definitively positive or negative effects (Midlarsky et al., 2008).

In addition to age, research suggests other unalterable factors of typical child adjustment to be the gender of the child and the number of children within a family. According to research done by Surratt in 2008, the disability experience is different for girls and boys regardless of the type of disability. Specifically, Surratt's research found that older sisters and younger brothers have increased risk in experiencing adjustment problems.

Number of children in the family also has an impact on response. Multiple research projects have shown that a higher number of children in a family decreases the pressure to achieve, increases shared activities, and causes children to use more “emotion-focused coping strategies.” (Surratt, 2008). Family 3 had a sense of these adjustment tendencies, having seen the affects of disability in other parts of their extended family; they decided to have another child after their disabled child to help take some of the caregiving burden off of their one typical child.

CHAPTER FIVE

Changes Over Time

It is very important to recognize how much of the response to disability can change or become more apparent as children grow older. In some cases, the positive effects of disability become apparent later in life, and in some the negative effects. The delay of these responses until later is to be expected as the adjustment process is never completely over, but it makes the coping process more complicated. "I didn't really realize the implications of having special needs siblings until college because that's when I got out of my home," said M8. "It didn't really hit me until my sophomore or freshman year of college, and it took years to put all the pieces together." Family 2 dealt with intense anger issues in their typical children mostly after they went to college. "That was harder to take than the diagnosis of Down Syndrome," said M2. "We didn't see that coming at all."

According to the Rossiter and Sharpe study, typical children may not realize or may deny the negative effects of disability until adulthood. Said M2 of her older daughter after she left for college,

She all of a sudden realized that she grew up very differently when these little boys came along. She did not have the household that a lot of her friends had experienced when she went to college. She hadn't done a lot and hadn't been able to do a lot because of the whole home situation, and she was mad at that. It took a good long time for her to get over that, for [her typical brother] to get over that.

M4 said that her middle daughter separated a significant amount after she was first married because she recognized the ease of spending time in the typical household of her in-laws.

It was a whole different story; they didn't have a disability in the house. You could sit on the couch and talk, watch TV, have normal conversations. There'd be a sense of...ease. And fun. And lightness. And our house wasn't as light or fun or easy. And she preferred that for a while.

However, in both of the previous examples, parents expressed that their children “returned home” after a while. They embraced their home lives, disability included.

As these examples showed in the end, studies have found there to be more negative response in the short-term, but a lasting positive response later in life (Rossiter & Sharpe, 2001). A study by Begun in 1989 (cited by Davys et. al in 2011) found that siblings aged twenty were more likely to report conflict with their siblings than were siblings who were over 21. Throughout this study, parents frequently expressed a desire that growing up with a disabled brother or sister would engender a greater capacity for compassion and sympathy in their children later in their lives. For some parents, they even expressed that they could already see these positive character traits in their typical children. Said F8 of his older typical son, "My hope is that his experience of growing up with [our disabled child] as a brother... that it gives him a compassion for people...that it would color his life in a good way that he sees people a lot more deeply rather than on a shallow level, that he can make judgments about people better than he might." Families 2 and 9 told stories about their children's voluntary involvement in disability programs, both as children and in their adult lives. M2 described that she could see instances of her typical children being better parents as a result of growing up with their intellectually disabled brother.

These families and others also described how disability had impacted their typical children's choice of spouse, or anticipated that it would impact this decision. Research done in 2005 found that relationships in siblings' homes and families as adults were

related to their upbringing in a home with a disability (Seltzer, Begun, Seltzer, & Krauss, 1991). However, another study found marital status and number of children to be unaffected (Davys et al., 2011).

CHAPTER SIX

Conclusions

Living with a disability is, as many of the participants of this study described it, a process. It is a life change that has daily impact, and the effects change over time. F1 described some of the changes in disability as evolutionary. As opposed to a one-time adjustment, growing up with a disabled sibling requires both initial and continuing adjustments every time this sibling grows and changes. When one combines the changes that disabled child goes through with the inevitable changes that all of the other members of the family will go through as they grow and mature, it becomes clear that a sibling's perspective on disability may never quite be consistent. There may be seasons of growth in love and compassion followed by seasons of bitterness or confusion. Though it can be difficult to have patience and easy to wonder if disability will only negatively impact one's children, examples that some of the families in this study gave can offer hope. Outside research as well as this parental report has confirmed that there can be long-term positive impacts of growing up with a disabled sibling, even in spite of conflicting negative emotions.

When considering all of the factors that play a role in typical child response to sibling disability, there are a myriad of interconnected issues that can seem complicated and difficult to handle. For parents in particular, it can be overwhelming to understand the personal responsibility that they hold. As both previous research and the testament of families participating in this study have shown, parental attitude toward disability is one of the most important factors in sibling adjustment. This seems to be the case because of

the influence that parent response has on so many areas, including parent ability to provide emotional support the family, integration of the disabled sibling into family and community life, and the sibling's perception of disability. Outside of the parent's attitude, the parent's choices regarding education, delegation of responsibility, siblings' community involvement, and parent-child relationship play a role in sibling response.

There is reassurance in previous research that seems to say that parents already have a sense of the needs of their typical children when facing the changes of disability. According to a 2009 study, parents expressed belief that their boys had a need for disability education, quality time with parents, knowledge in how to communicate with their disabled sibling, and a need to accept and love their sibling. Sisters were cited as needing parental attention and time to play (Kresak et al., 2009). These results, based on their agreement with findings of this study, are evidence that some families instinctively understand the needs of their typical children.

However, there are also other issues completely outside of the parent's control that also have major consequences for sibling response to disability, including type of disability and sibling age. Considering these uncontrollable factors, parents need substantial support to cope with their child's disability. More than providing evidence of positive future possibilities for children with intellectually disabled siblings or the power of parents in their typical children's lives, this study is a reminder for the communities surrounding these families that their support is absolutely necessary to facilitate the best response possible. According to one study, it is important to realize that parents of disabled children are vulnerable if the sources that they turn to for support are no longer there for them (White & Hastings, 2004). Surrounding communities can offer physical

and emotional aids to parents and children that equip them to deal with a disability. Schneider et al. assert on page 934 of *The Journal of Intellectual Disability Research*, “It becomes imperative that people working with families caring for adolescents gain an understanding of the dynamics of family routine and an appreciation for the unique demands the system places on families through its lack of predictability” (2006). Likewise, Sharpe and Rossiter urge, “Clinicians working with the families of children with chronic illnesses need to be aware that siblings are at some risk for negative psychological effects” (p. 707). Parents cannot adequately care for their children without outside support, and children are much more likely to respond more positively if the family as a whole is cared for.

Study Design

While the research was done with as much care and precision as possible to ensure that the following data would be complete and accurate, the conclusions drawn from this project are still incomplete. Certainly, conclusions drawn from one collection of research cannot apply universally. Furthermore, one must consider that the conclusions drawn in any social science project will inevitably be impacted by the researcher’s own personality and bias, the background of the participants, the overall demographic of the population being interviewed, and a variety of other factors. It is not the goal of this project to present a definite set of rules guaranteed to elicit a positive sibling response to disability; this would be unrealistic and dangerous. There are too many factors at play to guarantee a result when it comes to a child’s behavior; the reality of human nature means that people are often going to act and react in unexpected ways. Instead, the desired accomplishment of this project was to provide a resource for families

describing some of the factors at play in sibling response, the responsibilities of parents, resources available for parents, and the responsibility of the greater community when considering families dealing with intellectual disabilities. There will always be more research to add, more to know, more that is unknown or misunderstood. This project is one contribution to an ever-growing understanding the complex dynamics at play in families with both intellectually disabled and typical children.

One of the most obvious difficulties of this study is that it deals with a parent's perspective on what children are thinking. One of the specific difficulties in conducting parent interviews is the risk that parents are unable to see their children's internalizing behaviors. According to research by Sharpe and Rossiter (2002) as well as Surratt (2008), internalizing behaviors including anxiety and depression are among the common negative behaviors seen in disabled children. These internalizing behaviors may result from increased parental expectations for caregiving feelings guilt, need to compensate for a sibling's inabilities, parental inattention, or other factors, say sources cited in Sharpe and Rossiter (2002). One father described how his daughter went a year of her time in preschool without saying anything. "When we placed [our disabled son], just two weeks later- chatterbox." Also according to the 2002 study, "Frustrations arising from parental inattention or caretaking responsibilities may not be easily externalized by the healthy sibling into behaviors such as aggression, given the precarious health status of their brother or sister" (Sharpe and Rossiter, p 702). Instead, children internalize their frustrations (Davys et al., 2011). According to interviews done by Strohm in a 2005 publication, siblings feared that their own failures would put additional pain or burden upon their parents.

The pressure to achieve has been well-documented as one of the major contributing factors to internalizing behavior (Meyer & Vadasy, 1994; Surratt, 2008). Meyer and Vadasy described how these high achieving tendencies can be a positive or negative coping mechanism. The negative behaviors would be difficult to perceive in studies like these because the parents would, more than likely, not be as aware of these behaviors. Parents in this study were aware that there is a possibility of these things happening, but it is also likely that they may, by the child's own design, never be aware of these problems. Said one mother of her son, "He's not one that likes to talk about things, he holds everything in. I don't know if he's even to this day processed everything like he needs to." According to Surratt, "counselors should be cognizant of warning signs in siblings of children with disabilities who accept nothing less than perfection and find little pride or sense of accomplishment in their successes in academics and personal areas of their lives" (2008). However, parents in this study also expressed that their children did not seem to be overly concerned with excelling far beyond their peers, but tended to stay in "the middle of the road." Surratt's study said that siblings "were more likely to exhibit adaptive rather than maladaptive perfectionist tendencies. Furthermore, Meyer and Vadasy's study said that it was the children themselves, not the parents, who put the achieving pressure on themselves, not their parents (1994). It is important that parents are aware of the possibility of internalizing. It could be beneficial to conduct further studies from the child's perspective instead of the parent's to determine the prevalence of internalizing.

Reassuringly, research has found that sibling and parent reports of adjustment are not, according to some measurements, that different (Guite, Lobato, Kao, & Plante,

2004). Research indicates that a parent report regarding the wellbeing of their typical child tends to be the most negative (Sharpe & Rossiter, 2002). Results of this nature strengthen the positive outcomes discovered in this study, since multiple parent interviews suggested positive impacts in the lives of typical children with disabled siblings.

Furthermore, it can be beneficial to talk with a parent as an observer of the children's behavior because they were often able to see changes in their child's demeanor or responses in their child's behavior that the children may not have been able to pick up on themselves. Parents are also able to attest to the changes in their own behavior, accommodations they as leaders of the family made, internal workings of the marriage relationship, or other factors that would may not have been noticed by typical children that could have been interviewed; as a result, this study was able to take some outside factors into account that may not have been considered had parents not been interviewed. Despite these benefits, however, only the sibling can know exactly what they are thinking or feeling about the impacts of having a disabled sibling. Further studies should be conducted with siblings themselves, looking for themes running through their responses to disability, positive or negative impacts, etc. While the focus is technically on the siblings and what issues they deal with, they often don't fully understand the effects until they're adults.

One of the risks of interviewing only parents, however, is the possibility of parents projecting their personal feelings onto their children. A parent may assume that their typical child is experiencing emotions, negative or positive, that the parent experiences. A parent who views disability as a limitation in his or her own life would

likely assume that disability would also be viewed as a limitation in a typical child's eyes as well. Conversely, a parent who sees and expresses the positive effects of disability in his or her own life may assume that it has had positive impacts on his or her typical children as well.

Again, the way to most effectively fight the bias of parent projection would be to interview the children themselves. Obtaining logical, accurate, and useful information from younger children may be more difficult, but older children could provide very useful insight into the personal impacts of growing up with a disabled sibling. It would be highly recommended that someone expanding upon the research done in this study interview adults who grew up with an intellectually disabled sibling. This group of participants in research would, first of all, be capable of expressing their experiences clearly. Secondly, adults would more fully be capable of describing the full spectrum of factors that contributed to their response to disability as well as the lasting effects of having an intellectually disabled sibling. Because the full outcome of having a disabled sibling is not usually apparent until adulthood or even parenthood, adult siblings of intellectually disabled children would probably have the most complete perspective.

It would be recommended that future interviews still include elementary-aged children, and teens still in the home as well as young adults who are no longer living with their family, and adult children who are either single or have children of their own. While a study of this nature may be quite extensive, it would be necessary if one hoped to discover the self-reported factors for positive response that have affect across different life stages. This coincides with previous research findings that the full implications of sibling disability may not be understood completely by a child until he or she reaches

adulthood (Midlarsky et al., 2008). Additionally, research done by Midlarsky et. al in 2008 suggests that some of the inconsistencies in research regarding siblings of disabled children are a result of the vast gaps in developmental stages and ages of the participants. Other research has suggested that the inconsistencies in results are due to methodological and measuring differences as well as including a wide variety of disabilities in one study (Benson & Karlof, 2008). Narrowing the scope of the study to one specific intellectual disability could be more beneficial for that disability community, though the results may not be as generalizable. For some reasons, however, the method of only using parent responses necessary because the children in question may not have been old enough or mature enough to understand the implications of having a disabled sibling on their own life.

It would also be recommended that further studies be expanded to include families of more diverse racial, socioeconomic, and religious backgrounds. The participants in this family were predominantly middle class, Caucasian, Christian families. Financial situations are a significant factor in dealing with disability, but the lack of variation of income among families in the current study did not capture this distinction. Furthermore, it would be interesting to expand the participant pool to families with a less significant religious background than those interviewed for the current study. Considering the impact of faith that these families described, it would be interesting to compare this effect with other families who do not identify strongly with a particular religious system.

Another major contributing factor to the design of this study is the model through which research is conducted. According to Dykens, 2005, there are multiple models

through which response to disability has been studied over time. The psychopathological view with its “focus on maladjustment and dysfunction within families” caused research to be skewed toward negative results. The second model of stress and coping assumed that families would be stressed by disability and looked into what coping methods would be required in order for families to respond to the best of their ability; this method, however, still left out the possibility that there could also be positive benefits to disability that typical families may not experience. The last view of disability as described by one analysis of Dykens’ work, says that “The strength and resiliency of the family is emphasized in [the] third model as members adapt to change and challenges of daily life with a child with special needs, and then thrive as a family system” (Surratt, 2008). Executing the current research from this perspective made the positive perspectives on disability more visible in the results.

As with all studies, the researcher only knows what he asks. While the semi-structured format of the interviews allowed for the research to expand much more than a strict survey or questionnaire would have, the information obtained in this study was still entirely dependent upon the questions asked by the interviewer. It is impossible for the researcher to know exactly which questions individual parents will respond to the most readily, what will be the most effective manner of interviewing, or what unique circumstances may present in each family. In other words, you don’t know what you don’t know. However, the benefit of the grounded theory method used in this study is that it is much more open than a typical research study, allowing unexpected information to penetrate the research. While the researcher cannot know everything about what a family is going through or what their individual dynamics are, being open to the new

possibilities that families brought up during the research process was invaluable for ascertaining factors to disability response that may not have become apparent otherwise. This type of research would be highly recommended for anyone wishing to continue to research begun in this project.

APPENDICES

APPENDIX A

Interview Participant Information

Family 1 (F1 and M1): 8-year-old boy, 6-year-old boy diagnosed with PDDNOS (pervasive developmental disorder not otherwise specified, very similar to a mild version of autism), and 1-year-old girl.

Family 2 (F2 and M2): 37-year-old girl (married), 33-year-old boy (married), 26-year-old boy diagnosed with moderate Down Syndrome and partial verbal abilities, living at home, 24-year-old boy living outside of the home.

Family 3 (F3 and M3): 21-year-old girl currently in college, 19-year-old boy with severe autism currently living in a facility outside the home, 16-year-old girl living at home.

Family 4 (F4 and M4): 33-year-old girl (married), 30-year-old girl (married), 27-year-old diagnosed with agenesis corpus callosum, currently living in a group home and making weekly visits to her family. Also has seizures and requires with daily tasks and toileting.

Family 5 (M5): 9-year-old girl, 6-year-old girl with malformed, partially smooth brain, which causes motor, learning, speech, sensory, and emotional delays.

Family 6 (M6): 22-year-old boy at graduate school, 20-year-old boy at college, 15-year-old boy with a severe traumatic brain injury from a car accident, resulting in limited speech, limited memory, and delayed left side movements that necessitate use of a wheelchair.

Family 7 (F7 and M7): 6-year-old boy, 4-year-old girl with degenerative white matter disorder requiring full care and gastrostomy button feeding. She is also nonverbal.

Family 8 (F8 and M8): 19-year-old boy living at college, 17-year-old with severe autism that has made him nonverbal and other cognitive delays.

Family 9 (F9 and M9): 13-year-old girl, 10-year-old girl, 9-year-old girl with Down Syndrome, relatively high functioning with verbal abilities.

APPENDIX B

Interview Questions

How many children do you have? How old are they?

Can you tell me about the disability and when you first learned about it?

What was your initial response to the disability? Explain.

What was your previous experience with disabilities?

Describe the changes in your home life that took place after the birth/disability.

Describe immediate changes in your own attitude and mood. How did these change over time?

Describe other immediate changes in your perspective. How did this change over time?

How have your other children responded to your attitudes and perspectives?

How do your other children perceive the disability now? What have you done to help them learn about the disability?

Please tell me about the care your other children have provided to your disabled child/children.

What would you estimate is the amount of time per day you spend with your children?

In what ways would you say you interact with your children in similar ways and in different ways?

Have you found your faith background to be significant in helping your family to adjust?

Are you involved in any family support groups related to disability?

What has helped you most significantly to cope with the change of disability?

What has helped your other children to cope with the change of disability?

Have you found anything to be harmful to you or your children's ability to adjust to disability?

Do you know of anyone else who may be interested in participating in this research study?

(If disabled child is younger)

How old were your non-disabled children when your disabled child was born/diagnosed?

Describe your relationship with your other children prior to the birth/disability of your disabled child.

About how much time did you spend with your children prior to birth/disability?

Did you see this relationship change immediately after the birth/disability?

Did you see changes in your other children?

How did your other children react immediately?

How did your other children perceive the disability immediately? Did that change with the passage of time?

(If family has multiple disabled children)

Did having previously had a disabled child affect your response when you had another disabled child? Your other children's responses?

APPENDIX C

Informed Consent Form

Informed Consent to Participate in a Research Interview

“Special Responses: The Effect of Parents on the Family Dynamic and Sibling Response to Disability”

Principal Investigator: Emily Bertram, Baylor University

Co-investigator: Dr. Bill Hoy, Baylor University

The goal of this research project is to look into the family relationships surrounding disability. Disability has major impacts on families, but this impact can change depending on the family’s response. This project seeks to determine if the parents’ response has an effect on their non-disabled children, and if/how this response can foster a healthy relationship and family unit.

In order to look into this topic a little more, parents that have lived with both disabled and non-disabled children will be interviewed. They will be asked a variety of questions about their experiences having both disabled and non-disabled children, what changes it has brought about, what has made the experience more positive, and what they have learned or are learning in the process. The adult interviews are anticipated to last somewhere between one to two hours.

While it has been attempted to make the questions being asked sensitive to the topic, it is possible that some questions could bring up feelings of frustration, sadness, anger, or feelings of an invasion of privacy. If at any point during the survey you are uncomfortable, don’t want to answer a question, or want to stop the interview completely, that is okay. There will be no pressure or ramifications to you if you decide to stop the interview. This interview will be completely controlled by your comfort level. The interviews will also be conducted in a private environment in order to keep any information you share as confidential as possible. If you feel at any point that the difficulty of the interview merits the attention of a counselor, referral to a counseling service will be made available to you.

While these interviews will be recorded, all information will be kept completely confidential and password protected. Your responses will be assigned a random case number and any identifying information will be kept separate from these responses. The only people with access to the interview information will be the thesis advisor, Dr. Bill Hoy, and the principal investigator, Emily Bertram. However, because questions specifically about your home life and family interactions will be asked, any indication or suspicion of abuse must be reported to the appropriate law enforcement.

There is no compensation for participation in this interview, but the investigation seeks to use the input that you give to add to existing knowledge about living with disabilities. It is hoped that the completed thesis project will provide a small window into this type of family life and what a parent's role can be to make it as positive as possible.

For any further information about this study, please contact the following:

Emily Bertram, Student, Baylor University
Phone: (952) 769-7494
Email: emily_bertram@baylor.edu
Mailing address: 1709 S 15th Street Waco, TX 76706

Dr. Bill Hoy, Professor, Baylor University
Phone: (254) 710-2065
Email: bill_hoy@baylor.edu
Mailing address: Baylor University: One Bear Place #97202 Baylor Science Building,
Suite D-108 Waco, Texas 76798

If you have any questions regarding your rights as a participant, or any other aspect of the research as it relates to you as a participant, please contact the Baylor University Committee for Protection of Human Subjects in Research

Dr. David W. Schlueter, Ph.D., Chair Baylor IRB

Baylor University
One Bear Place #97368
Waco, TX 76798-7368

Dr. Schlueter may also be reached at (254) 710-6920 or (254) 710-3708.

By signing here, I acknowledge that I have read the above information and agree to proceed with the interview process as described.

Participant Name (Printed):

Participant Signature:

Date:

*A copy of this agreement will also be given to you for your records.

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