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Parenting a Child with a Developmental Disability: An Autoethnographic Approach to Sensemaking

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PARENTING A CHILD WITH A DEVELOPMENTAL DISABILITY:
AN AUTOETHNOGRAPHIC APPROACH TO SENSEMAKING

by

Danielle Sparrow

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ABSTRACT

PARENTING A CHILD WITH A DEVELOPMENTAL DISABILITY: AN AUTOETHNOGRAPHIC APPROACH TO SENSEMAKING

by

Danielle Sparrow

The University of Wisconsin—Milwaukee. 2017
Under the Supervision of Professor Erin Parcell

Each year, approximately one in six children are diagnosed with a developmental disability (DD) in the United States according to the CDC (Developmental Disabilities, 2015). In 2015, my daughter fell severely ill with encephalitis and became part of this statistic. Parenting a child with a DD can be an extremely isolating (Naseef, 2001) and even scary experience. However, storytelling helps individuals process experiences, connect with others, and shed light on their perspectives. Parents can become informed through these shared experiences, build supportive communities, develop resilience, and transform their perspectives. Using the qualitative research method of autoethnography, I approached my work through narrative to systematically analyze my experience as a mother navigating the many social and emotional facets of my daughter's illness and subsequent DDs. Using the parent transformation model (Scorgie, Wilgosh, & Sobsey, 2004) and relational dialectics theory (RDT) (Baxter & Montgomery, 1996) as sensitizing concepts, I explored my experiences through a parent-perspective lens (King et al., 1999). Ultimately, I wanted to connect with others whose lives have been touched by childhood DDs, and to play a part in the greater collaboration of sensemaking.

Keywords: autoethnography, developmental disability, family communication, health communication, parent-perspective, relational dialectics theory, qualitative research, transformation process model

To

My beautiful daughter Lily, the brightest light in my life.

My husband Kevin, the solid rock beneath me.

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Parenting a Child with a Developmental Disability: An Autoethnographic Approach to Sensemaking

Chapter 1

Introduction

About a year and a half ago, my husband and I nearly lost our then five-year-old daughter Lily to a rare autoimmune disease called acute disseminated encephalomyelitis (ADEM). ADEM is the result of the body's immune system attacking itself, causing inflammation in the brain and spinal cord. After five weeks at Children's Hospital (three of those being in the PICU), we were finally able to take our daughter home. I wish all illnesses were wrapped up into two parts: Sick and better. However, once our daughter was considered "better" we were presented with an entirely new set of challenges. Instead of being thrown back into life where we had left off, we were sent down a life-altering road where the residual effects of her illness acted as tiny road blocks to a "normal" way of life. Lily had to painstakingly re-learn how to walk and talk; and today she suffers from subsequent developmental disabilities (DDs), which makes some of the basic tasks most kids take for granted at her age, a struggle. Parenting a child with DDs has required us to adapt to an entirely new way of caregiving and advocating; and since many of the mainstream parenting books do not account for DDs, much of our journey has been trial and error. Other areas of my life have also been challenged, such as navigating relationships under these new circumstances and negotiating my identity as a parent.

For a long time, I viewed my family's situation as simply unfair. I burst at the seams with empathy daily; I shudder every time I see or hear an ambulance in my neighborhood, and I panic every time my daughter complains of any kind of ailment. I have also been slapped with uncomplimentary labels – worrywart, stress-case, and I have even been associated with the term helicopter mom once or twice. However, as an escribitionist and master's student in the discipline of communication, I have been unknowingly combining my love for journaling with my love for research, and am growing more resilient through this type of sensemaking. First, I find that by reflecting on my experiences, I can uncover positive attributes within the adverse contexts of illness and disability. Second, I find that the knowledge gained through the literature offers me a sense of control while the knowledge I gain through other parents offers relatability and community. While I would give anything to relieve my daughter from the struggles that her DDs place on her, I also would not change anything about her. She fills my life with so much happiness. Yes, my stress and anxiety levels are very high and yes, sometimes I still feel isolated. However, I have grown into a strong advocate for my daughter, I became a trained support-parent for Parent2Parent of Wisconsin, my husband and I are tighter than ever, and I have more patience than I ever knew I was capable of.

There is a need for research on childhood disability through the parent-perspective. First, parents are their child’s best advocates. Parents can describe the day-to-day experience of their young child regarding how the DDs affect them and what they need to be successful. Second, it is important to understand that parents experience the disability of their child in their own ways; therefore, it is through these narratives that society can learn what parents need to feel supported so that they can, in turn, be supportive of their child. According to Brown, Goodman, and Küpper (2014), much of the research findings are based on group data; however, “what is true in a research sense may not be true for [every] family” (para 2). Through the parent-perspective (e.g., McGill, 2003), I believe we can uncover the hidden elements of DDs. Furthermore, qualitative research in this area demonstrates the importance of holistic services and care (e.g., King, King, & Rosenbaum, 1999; Pelchat & Lefebvre, 2004).

For this project, I choose to write an autoethnography (Ellis, Adams, & Bochner, 2011) because I wanted to provoke sensemaking and community building between other parents of children with DDs and myself. I gave a voice to parents of children with DDs so that policies can be better informed and progress can be made toward providing services that address the entire family and the whole child, as opposed to the disability alone. My hope is that through reading my autoethnography, instructors, healthcare providers, and community members will gain a better understanding of what having a child with DDs can be like from the parent-perspective.

When my daughter first became ill with ADEM, I needed to share my story as a way of seeking support. I blogged, shared updates on Facebook, and lightly engaged with others in online support groups. This way of sharing was helpful to me on an emotional level, and I believe that my openness worked to help others, as well. However, so much has happened over the past couple years and the snippets of my story spread out across different platforms over time do not reveal the big picture. By doing an autoethnography, I could gather up all the tiny pieces, such as blog posts, text messages, photographs, videos, memories, and conversations with others, then combine them together into a written collage. While ethnography is described as "a sociocultural interpretation of data collected through direct observation [of others]" (Miller-Day, 2004, p. 19), and autobiography is a story written about the self, based on memories of lived experiences, autoethnography is a story about one's *own* experiences and an analysis that works to make meaning of them while also exploring how these experiences can socially and culturally relate to others (Ellis, 2004). My autoethnographic collage is an analysis of my experiences that can also aide in the understanding of human experiences by detecting patterns through inquiry and theory. There is a common perspective in our society that 'everything happens for a reason.'

I don’t know if I subscribe to this way of thinking or not, but I do feel a push to make something out of my experiences by playing an active role in what becomes of them.

Organization of Study

The above section was an introduction to my experience as a mother with a child who endured a health crises and consequential DDs, the importance of this research, as well as why I choose the method of autoethnography for my thesis. In the next chapter, I briefly review and discuss the background literature connected to my conceptual framework, sensitizing concepts, and research question. In chapter three, I explain the methodology and my reflections as a researcher doing an autoethnography in the field of health communication. Chapter four contains my researcher reflections before I report my findings in chapter five, which is the autoethnography itself. Chapter six offers a more formal analysis comparing the literature with the parent-perspective on childhood DDs and concludes with my plan to progress the current study into translational research, as well as my final thoughts on this project.

Chapter 2

Background Literature

The cause of my daughter's illness is still unknown but doctors say that it possibly stemmed from the measles vaccination, which she had received four weeks prior. Her treatments for ADEM included a cocktail of antibiotics, an antiviral medication called Acyclovir, intravenous corticosteroids (Prednisone), and daily plasmapheresis treatments through a Mahurkar catheter that was surgically inserted into her neck. In addition to those treatments, she received intravenous medications to eliminate acute and remote symptomatic seizures and sympathetic storming (episodic stress response causing exaggerated dystonia). After five weeks of in-patient care at the Children's Hospital of Wisconsin, my daughter was discharged with mild physical and developmental disabilities, such as gait abnormality and dyspraxia.

Why did I decide to share the complicated medical details in the literature review section? I wanted to create a temporary disconnect that demonstrates how a person's communication drastically changes once they enter the process of living through an experience that many cannot relate to, and how this change can lead to communication breakdowns. Everyday talk becomes more specialized in topic and the medical jargon is often distracting to the listener and lost in translation. The autoethnographic text is a bridge of understanding that refuses to be confined within the boundaries of traditional research. Autoethnography with interviews allows for multiple voices to co-exist within one text. Specifically, medical jargon, parent talk, and social science theory can be presented in a way that demonstrates the multiple layers that make up any given human condition, such as disability. Rather than simply presenting illness and disability according to medical research, the current study describes in layperson terms how parents experience these conditions while simultaneously working to make sense of these experiences according to theories in the field of communication.

Communication plays a significant role in how disabilities are viewed by society. In the next several sections, I review how the research is beginning to expand its focus to include the perspectives of the parents regarding how a child's disability affects the family as a whole, and how the well-being of parents directly affects the care and well-being of the child. Another important point I introduce is how society's negative perspectives of disability is both harmful and isolating to children with DDs and their families, which underscores my overarching argument that the voices of parents need to be heard so that families of children with DDs can be better supported.

Communication Concepts Surrounding Childhood DDs

The role of communication, within the context of healthcare and how it affects the way medicine is practiced by healthcare providers, is an important one (Thompson, Parrott, & Nussbaum, 2011). Furthermore, research in health communication has seen more growth in recent years than any other area of communication studies (Thompson et al., 2011). However, much of the literature surrounding children with DDs resides in medical-focused publications rather than those from the field of communication. For this reason, much of the literature I review is outside of the field, but focuses on communication themes and concepts that surround the experience of parenting a child with DDs. Examples include: (a) familial roles during health disparities (e.g., King, King, Rosenbaum, & Goffin, 1999; Raina et al., 2004), (b) stress associated with parenting a child with a DD (e.g., Bella & Garcia, 2011; Dunn, Burbine, Bowers, & Tantleff-Dunn, 2011), (c) isolation and the importance of social support systems (e.g., Lovell, Moss, & Wetherell, 2012; Woodgate, Ateah, & Secco, 2008), (d) resilience (e.g. El-Ghoroury, 2012; Heiman, 2002; McConnell, Savage, Sobsey, & Uditsky, 2015; Naseef, 2001), and (e) the re/construction of identity during and after a health crisis (e.g. Heisler & Ellis, 2008; Scorgie & Sobsey, 2000; Scorgie, Wilgosh, & Sobsey, 2004).

While the literature highlights feelings of stress and isolation felt by parents of children with DDs, a newer theme that has begun to surface in the literature is how parents talk positively and acceptingly about their children with disabilities (Raina et al., 2004). This positive-focused talk differs greatly from the common medical model of disability, which focuses on disability as a barrier that needs to be treated (Siebers, 2008). The medical model is incomplete because it does not account for the real-lived experiences and emotions of the child with DDs and their families. When we only treat and support people based on their diagnoses or symptoms of an illness and/or disability, we fail to meet and support all their other needs, and in fact, we may do more harm than good. According to Heiman (2002), parents are calling out for more supportive resources.

Child-centered versus family-centered research. Much of the research on childhood DDs focuses on the child. While this allows for more insight than the medical model approach, it still neglects how the family factors into their care, as well as how to meet the needs of family members. Miller-Day (2011) points out the interdependence between family and health. El-Ghoroury (2012) explains that it is important to get to know the individual with a DD for who they are underneath their diagnosis. A child-centered approach to research aims to accomplish this by assessing children with DDs more holistically. This approach works to identify individual strengths of children with DDs and develop personalized goals (El-Ghoroury, 2012). While this holistic view of children with DDs is a positive step forward, the perspectives of family members continue to be overlooked in much of the literature. When a child suffers from a health crisis, the entire family experiences it (Bella & Garcia, 2011). Unfortunately, there is very little family-centered research on the interconnectedness of family and health, such as how parents experience the illness or disability with their child (Fisher, 2011; Miller-Day, 2011), and this is especially true in the field of communication (Miller-Day, 2011). King et al. (1999) claim that "only by truly understanding the experiences that affect parents' emotional well-being will we be able to meet parents' needs effectively and thereby improve outcomes for children" (p. 52).

Family-centered research considers the wellness of the whole family in addition to the wellness of the child affected by a DD. One example is how siblings feel about and cope with the illness of their brother or sister, as well as how they cope with the focus of their parents being on the child with the illness or DD. Another example, and the focus of my research, is on how parents feel about and cope with the illness or DD of their child. The family-centered approach offers a more comprehensive look at the whole child through the lens of family members, and more specifically parents (King et al., 1999). This is important because there are many factors that play a role in the wellness and development of a child with a DD. One of those factors is the mental wellness of the child's parents (El-Ghoroury, 2012; King et al., 1999). How a parent handles their child's DD directly affects the progress of that child (El-Ghoroury, 2012). For example, some parents are in denial (Heiman, 2002) and foster the hope that their child will recover from the DD (El-Ghoroury, 2012). This mindset prevents them from accepting the reality of their child's DD, which can in turn prevent them from advocating for their child's needs and realizing their strengths (El-Ghoroury, 2012). Family-centered research invites the perspectives of family members who are closely connected to the child with DDs, which gives healthcare providers a look at the bigger picture. With this insight, healthcare providers can help parents accept the reality of their child's DD (El-Ghoroury, 2012), while also embracing a positive outlook (Corman, 2009; Schwartz & Hadar, 2007).

Research that has taken a family-centered approach also shows that parents who receive social support are able to manage stress more effectively and, in turn, better adapt to their role as good caregivers (Dunn et al., 2001; Gallagher & Whiteley, 2012; Miller-Day, 2011; Raina et al., 2004). Research has only begun to uncover the complexities of childhood DDs. Additional research from the parent-perspective will shed more light on this topic so that we can extend the conversation across disciplines.

Social support and isolation. Despite our understanding of the importance of social support for parents of children with DDs, researchers continue to find that parents do not receive (enough of) it, which often increases their feelings of isolation (Heiman, 2002; Kranowitz, 2005; Woodgate et al., 2008). The conceptual model of factors influencing psychosocial outcomes for parents of children with disabilities was utilized to pinpoint various factors that affect the emotional well-being of parents of children with DDs (King et al., 1999). King et al. (1999) gathered data exclusively from parents' perspectives and was the first to identify the vital role social support has on the emotional well-being of parents of children with DDs. According to this model, the disability parameters (i.e., severity of disability, child's functional independence) do not directly impact parents' emotional well-being. Instead, a variety of other factors directly affect these parents' well-being, such as demographic factors (i.e., education, employment, income), types of professional caregiving (i.e., informative, supportive) provided and the satisfaction with said care, social-economic factors (i.e., family functioning, social support), and psychological life stressors (i.e., burden, child behavioral problems) (King et al., 1999). This model was created to better understand in what areas parents need support and how varying factors affect their emotional well-being (i.e., depression, stress). I suggest using this model as a tool to understand how other factors (e.g., reduced economical stressors, holistic family-focused support, social support groups for parents, relatability, child behavioral support) positively affect the emotional well-being of parents of children with DDs (e.g., resilience, positive reappraisal, a sense of community). For the current study, I demonstrate how the right kind of social support, which is based on relatability, is linked to my emotional well-being. The more I can relate to another parent, the better I feel about my experiences and myself.

By doing autoethnography, I found that despite receiving a lot of interventional support for my daughter, such as healthcare benefits, and medical and rehabilitative care, I continued to struggle emotionally. The literature demonstrates that parents receiving support can continue to feel isolated because they are not receiving all the *types* of support they need. While most parents have access to familial psychological support, they find that the significant changes in their social lives leave them feeling disconnected from others (Heiman, 2002). My autoethnography reveals what real-life factors affect my emotional well-being, which I hope will prove the value in continued research on the parent-perspective.

New Directions: Shifting from Negative to Positive

Much of the literature on parenting a child with a DD has focused on the negative aspects, such as how stressful it is (e.g., Bella & Garcia, 2011; Dunn et al., 2001; Murphy et al. 2007; Raina et al., 2004; Woodgate et al., 2008). According to Garland, Gaylord, and Park (2009), people are able to find positives within adversity: “Positive reappraisal is an active coping strategy rather than a defense mechanism used to repress or deny” (p. 39). Although this research points out the importance of social support, the potential for positive reappraisals of parenting a child with a DD is an overlooked area. So then, is it possible that this dominating negative framework is limiting our research and shaping our understanding?

McConnell et al. (2015) claim that it is the sociocultural perspective, as opposed to the parent-perspective, that assumes parenting a child with DDs is a problematic and negative experience. Scorgie and Sobsey (2000) describe how healthcare professionals perpetuate this behavior by "catastrophizing" disability, which results in care that targets the "problem" rather than helping parents adjust to their new life with a child who has DDs. According to Kearney and Griffin (2001), the medical literature continues to view disability from a "tragic perspective," which "influence[s] professional interpretation of parental responses to having a child with developmental disability" (p. 583). The conflict with these approaches is that parents do not always see their child's DDs as a problem. Trute, Hiebert-Murphy, and Levine (2007) conducted a study on parental cognitive appraisal of positive impacts of DDs on the family. They found that parents can simultaneously make both positive and negative appraisals of DDs. Despite the pain that goes along with parenting a child with a disability, parents have another reality — one where lives are managed "cheerfully and constructively" (Kearney & Griffin, 2001, p. 583). The authors describe the tensions between joy and sorrow that parents of children with DDs experience. Parents of children with DDs "emphasize their experience as being positive," and describe their children as a "state of joy" (p. 586); however, their experiences with other people are portrayed as negative. Specifically, parents felt written off, rejected, isolated, and hurt by professionals, family members, and friends (Kearney & Griffin, 2001). As a parent of a child with DDs, I want to be supported through learning how to live with it, rather than pushed to fight against it. I want to help my daughter be successful and happy in this world but without feeling the social and emotional pressure to "fix" her. Kearney and Griffin's (2001)

Between Joy and Sorrow: being a parent of a child with a developmental disability model describes the tensions that parents feel between the joys of parenting their child and the sorrows of reinforced negativity coming from others. In face-to-face discussion style interviews with six parents, Kearney and Griffin (2001) report that parents specifically described negative messages of hopelessness from providers, friends, and family, which led to feelings of isolation. However, parents talked positively about their children and about their experiences with them. For example, parents talked about their children "with admiration, love and optimism," and described how their children made them 'better people' (Kearney & Griffin, 2001, p. 586). This model really speaks to what my research is about. The negative perspectives of others can influence how we feel (e.g., emotionally, psychologically) and behave (socially, parentally); however, through relatability and positive support, I have recently felt more empowered, hopeful, and happy.

When the surrounding discourses point in one dominating direction (i.e., the negatives), it is easy to view our own situation through that same lens. However, as soon as we start questioning those perspectives, we come to realize that we have our own interpretations of what disability means for our child, as well as for us as their parents. The literature led me to reflect on how my perspectives were influenced and how I began to change the way I talk about my experiences as a parent of a child with DDs. For example, during the early stages of my research, I struggled with an internal conflict that I could not quite put my finger on. I knew that I was making a lot of solid, and even true, points; however, something did not *feel* right. My early drafts painted a picture of despair. I was not writing from within; instead, I let the dominating literature, the professionals' concerns, and the negative remarks from others guide my work. I focused on my worries about her physical abilities, her academic success, and her emotional intelligence. I continue to worry about these things, everyday; however, I am much more caught up in the beauty of my daughter than I am in her DDs. Lily has the kindest heart and the most colorful imagination. While the pain of almost losing her, and the fear of it happening again is all very real, I relish in the gift of her existence daily – especially in the mornings. When my alarm clock goes off, I tickle her to the tune of the song that fills the air until she wakes. I always hit the snooze button and snuggle up next to her while she chit-chats about last night's dreams and her world of wonderment.

In summary, scholars have begun to make the shift from the examination of negative impacts to that of positive ones regarding parenting a child with DDs. Research is beginning to find that when given the chance, parents report more on the overall positive impacts of parenting a child with a DD than they do negative ones (e.g., Kearney & Griffin, 2001; McConnell et al., 2015). Parents' positive interpretations about raising children with DDs offer a new look at what life is really like for these families. This "insider" point of view can inform society and healthcare professionals as to what services and types of support are most beneficial. Pennebaker and Smyth (2016) claim that writing can help us change the way we think about the world. Going through this process has been an eye-opening experience, and I am grateful for that. It took writing this autoethnography to realize that I was allowing the perspective of others guide the way I talked about my daughter (e.g., sorrow, despair, and doubt; Kearney & Griffin, 2001).

New Directions: Situating the Parent-Perspective in Health Communication

Very little literature focuses on the parent-perspective of having a child with a DD. What does exist mostly comes from disciplines outside the field of communication, and much of the data comes from surveys or structured interviews with parents of children with DDs (Raina et al.,

2004) as opposed to qualitative studies involving parents. There are several popular press books written by parents of children with disabilities (e.g., Adams, 2013; Cawley, 2010; Naseef, 2001) covering the topic of parenting a child with a disability, not to mention a flood of DD-related blogs online, such as Shut Up About Your Perfect Kid (www.shutupabout.com); however, it is a rarity that academic research *about* parents is conducted *by* parents of children with DDs (at least explicitly). The parent-perspective is a powerful tool that can guide healthcare providers, social workers, and educators toward developing and providing better programming and services for families whose lives are touched by DDs. Specifically, Schwartz and Hadar (2007) found that parents "express positive thoughts and feelings about their experience… and need to be encouraged to do so" (p. 280). Based on these findings, the authors point out the importance of healthcare professional support and how they should help parents find the positives of parenting a child with DDs.

As a scholar and parent of a child with a DD, I would like to see more scholarship about childhood DDs written by parents who have experienced it first-hand, and so I heeded my own call. In the following section I discuss the autoethnographic approach to research, as well as how it can contribute to knowledge of how the parent-perspective differs from dominating research themes (e.g., negative appraisals of DDs).

Chapter 3

Conceptual Framework: Autoethnography

I chose the conceptual framework of autoethnography to make sense of my experiences as a mother of a child with DDs, and to contribute to the expansion of research derived from "the actual voices of the researcher and the researched" (Burnier, 2006, p. 412). Doing autoethnography is a unique process because it combines characteristics of autobiography with ethnography (Ellis et al., 2011). Tracy (2013) describes it as "the systemic study, analysis, and narrative description of one's own experiences" (p. 30), yet the self and culture are interdependent, meaning that without one you cannot have the other (Grant, 2010). Grant (2010) states that "culture is expressed through self" (p. 113); therefore, it makes sense that individual lived experiences revealed through an autoethnographic approach would work to shed light on the different parts that make up the larger cultural context (Ellis et al., 2011). By "blending the personal and scholarly" (Burnier, 2006, p. 413) the personal story becomes "vital data for understanding the social world being observed" (Anderson, 2006, p. 384). According to Chang (2016), there has been an "explosion of autoethnographies in health research" (p. 449). For example, in *Final Negotiations: A Story of Love, Loss, and Chronic Illness*, Ellis (1995) takes us on an intimate exploration through her relationship with a professor from graduate school, detailing how she experienced all the stages of emphysema alongside him. Spieldenner (2014) uses autoethnography to describe living with HIV. Wilbers (2015) depicts her experiences as the daughter of a mother with chronic pain, and the stigma surrounding opioids. Miller-Day (2011) edited a compilation of autoethnographies about families going through chronic disease or a health crisis together. There are popular press books that take on an auto/ethnographic approach as well. In *Seeing Voices*, Sacks (1989), a physician and professor of neurology, describes the world through the lens of deaf people. In *Riding the Bus With My Sister*, Simon (2003) takes us on a year-long journey as she observes and reflects on the life of her adult sister who has DDs. As autoethnography continues to grow in popularity, scholars can learn the ins and outs of doing autoethnography in Bochner and Ellis (2016) new book *Evocative Autoethnography: Writing Lives and Telling Stories*. Regarding childhood DDs specifically, autoethnographic research has the potential to inform healthcare policies, which can help providers better understand how their behaviors and actions impact patients beyond medical care (Peterson, 2014).

The autoethnographic approach is situated within a theoretical framework that guides the writer's reflections (McIlveen, 2008). While traditional forms of research often claim objectivity arguably through a precise lens, autoethnography is subjective and offers a wide lens through which to view the world (Ellis et al., 2011). This subject-object combination gives an advantage to the autoethnographer, who has access to information that would not otherwise be available to research (Chang, 2016). Becoming a parent is a life-altering experience. Having a child with a DD is another one, and like any life-changing event, you can try to imagine it but you will never truly know what it feels like until you have experienced it yourself. Conventional research can offer a lot of knowledge; however, the perspective is limited in the sense that the voice of those being examined is not always heard. Bostic (2010) asks the question, "when research produces data, do these data truly represent the realities of children with disabilities?" (p. 144). Autoethnography provides a lens that facilitates a deeper understanding for a broader audience (Ellis et al., 2011). Bostic (2010) argues that research must expand on the data so that we can truly understand the needs of families. Emerson (2003) echoes Bostic's concern, explaining that raising a child with a DD is complex and that the real-life outcomes need to be explored. What better way to expand the data than through the research method of autoethnography?

Summary of Study

Research confirms that raising a child with a DD is stressful and even isolating at times. Much of the literature on childhood DDs does not account for parents' experiences raising children with DDs, and what does exist focuses on the negative aspects rather than positive ones (Ryan & Runswick-Cole, 2008; Trute et al., 2007). There is a disconnect because parents of children with DDs "respond to the emotional and caretaking challenges… with positive coping and resiliency" (Trute et al., 2007, p. 1). Another problem is that negative assumptions (e.g., children with DDs are disabled, or incapable of living a full life) shape the way DDs are understood by society (Cherney, 2011). Such assumptions do not accurately portray the reality of people with disabilities. The parent narrative offers a holistic view, which can enrich society's perspectives surrounding childhood DDs (El-Ghoroury, 2012).

Bochner (2015) urges researchers not to prove why, but rather to demonstrate "how things happen in families" (p. 422) so we can better understand the process of people's experiences. Autoethnography enriched with theory is one way to find out the "how" because it adds perspective and value to research by offering an in-depth view into individual real-life experiences, as opposed to generalized analyses (McIlveen, 2008). Thus far, the overall literature points out the positive impacts of support systems and family-centered caregiving, and it calls for a family-centered approach. With more comprehensive research that demonstrates *how* things happen, we can begin to understand what needs to be explored next.

El-Ghoroury (2012) stresses the importance of narrative inquiries, such as autoethnographies, because they "focus on an underrepresented area in the literature… [and] can be valuable by informing healthcare professionals about the experiences of parents (and by extension, the individuals themselves)" (para 3). As a scholar in the field of communication, I hope that my own autoethnographic narrative will contribute to this area of research because I believe that through the performance of narrative we can uncover how storytelling functions within the practice of communication (Langellier & Peterson, 2011) and come to realize how it contributes to real-life experiences.

Sensitizing Concepts

My autoethnography analyzes the day-to-day realities of parenting a child who underwent a severe illness that lead to DDs. Using the parent transformation model (Scorgie et al., 2004) and relational dialectics theory (RDT) (Baxter & Montgomery, 1996) as sensitizing concepts, I demonstrate how my communication behaviors have changed throughout the process of doing this autoethnography. Below I offer a brief overview of each sensitizing concept.

Parent transformation model. Parents of children with DDs are more likely to associate their experience with positive outcomes rather than negative ones (Scorgie et al., 2004). Scorgie et al. (2004) developed the parent transformation model, which describes three interconnected processes of transformations that parents go through when they have a child with a DD. The first process, image-making, addresses questions of identity, such as how parents construct new images of themselves and of their children after a DD diagnosis. The second process is meaning-making, which addresses how parents work to make sense of their experiences to shift their perspectives to what is most important in life. The third process is choice-making, which addresses how parents cope and relate to others. Using this model, I was able to pull signs of transformation from my data, which I used to describe my own process of transformation.

Relational dialectics theory. Relational dialectics theory (RDT) explains that relationship partners are constantly negotiating contradictions within and through their communication experiences (Baxter & Montgomery, 1996). Baxter and Montgomery (1996) refer to these contradictions as dialectical tensions — or more specifically, tensions that lead to inconsistent communication behaviors occurring between people. These dialectics include openness and closedness, certainty and uncertainty, and connectedness and separateness. The history and context of a relationship each play a role in how people communicate with one another, as well as how successful that communication is. RDT gauges the competencies of communication between people based on their history and context. RDT has been used in studies related to family and health; for example, communication scholars have used RDT to understand the communication of families grieving the loss of a child (e.g., Golish & Powell, 2003; Toller & Braithwaite, 2009). For families raising a child with a DD, grieving is often a part of the process of transformation. For example, when my daughter was born premature and with a skull condition called craniosynostosis, I had to grieve the loss of a "normal" way of life. Our daughter's milestones were delayed and we spent many of our afternoons at the clinic rather than at the park where all my other mom friends were. When my daughter fell ill with ADEM we had to grieve the loss of who our daughter used to be while embracing the joy of having her live through this awful illness. For my autoethnography, I explored the idea that I experience/d contradictions (e.g., autonomy–connection, openness–closedness) and negotiated my patterns (praxis) of communication. Bochner (2015) argues that "we need to know *how* families manage and work out the contradictions they face" (p. 422). This autoethnography hopefully demonstrates the how by offering a dialectical perspective that works to make meaning of my experiences within the particular sociocultural context that I live in (Baxter, 2011).

Another concept within RDT that I plan to focus on is praxis. This idea describes how people tailor their communication with others and how they change as relationships grow. I talk with others about my experiences in order to make connections and build relationships. Over time I have begun to tailor what experiences, or what parts of an experience I share with people. Specifically, it is through my interactions with others that I learn when and where (in terms of parenting topics) I can achieve relatability through talk. Today I am more careful about my communication choices so that I can further develop all relationships with the understanding that not all conversations are meant to fulfill the same purpose. I privilege closedness over openness at times when I fear that my search for relatability will be unsuccessful. This way, I protect the friendship by not placing undue expectations and I protect myself from sharing information that will lead to feelings of isolation (e.g., my friend does not understand so I am alone in this experience) and vulnerability (e.g., feelings of regret for sharing information that should have been kept private, fear of judgment from those who cannot understand).

Research Question

Based on my sensitizing concepts coupled with my review of the existing literature, I began with the following guiding question while conducting my analysis:

RQ: What is my communicative experience with being a mother of a child with an illness and DDs?

Chapter 4

Method

A researcher's background shapes their perspective of the world and their approach to research (Tracy, 2013). Tracy (2013) explains that autoethnography is "the systematic study, analysis, and narrative description of one's own experiences, interactions, culture, and identity" (p. 30). By doing an autoethnography, I have combined qualitative research with a first-hand view into the unique world of parenting a child with an illness and subsequent DDs. Keeping concepts such as the parent transformation model and relational dialectics theory as sensitizing concepts, I wanted to take the opportunity to demonstrate how research and self can blend together to analyze the processes of communication as I worked to make sense of my own experiences. I explored a variety of personal, public, and researcher-generated texts, such as my diaries, blog, and transcripts of interviews with other mothers of children with DDs. I looked for themes by doing an inductive analysis of my field notes.

Existing Data and Artifacts for Autoethnographic Analysis

I have been documenting my experiences as a parent since the day I received my first ultrasound picture. While I was pregnant and during my daughter's early years, I wrote her letters to her on postcards. Once she became severely ill with ADEM, I began to write more for myself by keeping a personal diary. I also began to share my story more publicly through a blog (i.e., Caringbridge website). As she began to heal, I began to blog less; however, I continued to share my journey as a mother of a child with a DD on social media platforms and in online support group forums. The very writing of this proposal itself prompted me to revisit some of these writings, and I found that the combination of what was/is shared versus what was/is kept private tells a more comprehensive story of what it is really like to parent a child going through a health crisis and DDs. According to Tracy (2013), "some of the best ideas for qualitative research come from your personal life" (p. 10). I did not plan to write about my experiences until months after my daughter was released from the hospital and even then, I had not yet heard of autoethnography. Once proposed to me by Professor Erin Parcell, this method immediately felt like the right fit for me. Langellier and Peterson (2011) say that people construct meanings and claim identities through narrative.

Through my collected artifacts and data, I reflected on my experiences the way one does when browsing through a photo album. I continuously wrote fieldnotes about my experiences. Specifically, I wrote reflexive memos in the margins of my data, and I kept a reflexive notebook where I wrote about what it felt like to revisit my experiences, and how writing, reflecting, and interviewing affected my perceptions and communication behaviors with others. For example, I wrote about feeling less insecure than I used to feel when talking with friends who have typical developing children. Similarly, I wrote a memo in the margins of one of my interview transcripts that noted how this mom helped me realize that we do not need to share all our experiences as mothers of children with DDs with our peers. Instead, we can choose to discuss other topics, while saving our child-related stories for someone who can relate to them. Doing autoethnography has revealed how my parent-perspective has changed throughout this process.

Choosing stories. One of the features of doing an autoethnography is deciding what to write about. Unlike writing a biography, much more research goes into doing an autoethnography. Following Tracy's (2010) eight "big-tent" criteria for excellent qualitative research, I began to sift through my data. The first criterion for quality is having a worthy topic, which claims that the topic should be "interesting and point out surprises" (p. 841). With over 200 hundred pages of personal data, fieldnotes, and interview transcripts, narrowing down the themes for this project was a tedious task. My focus with was to find themes within my own data, and within the data from my interviews, then locate any surprising similarities and differences between the two sets of data.

The second criterion described by Tracy's (2010) is rich rigor, which demonstrates validity (p. 841). I chose examples from my data where I could recall the experience with accuracy. From the interview data, I chose examples that I fully understood, and that related to one of my themes or sensitizing concepts.

The third criterion is sincerity, which Tracy (2010) describes as "being honest and vulnerable through self-reflexivity" (p. 842). My story, if nothing else, is sincere. I followed up with my participants to ensure that I was also being sincere and accurate in my portrayal of their experiences by conducting member checks.

In the social sciences, credibility might be one of the most important criterions to achieve. Tracy (2010), describes this criterion as referring to "trustworthiness, verisimilitude, and plausibility of the research findings" (p. 842). Since this is an autoethnography, much of what I wrote about can be observed through my life, as well as through my blog. When considering what to write about, however, I was careful to not break the trust of my daughter. More than anything, I wanted to share my story without doing any emotional harm to my daughter. Specifically, I kept in mind that this will be published and available to the public and therefore, I was careful not to include any stories that could embarrass her or negatively intrude on her right to privacy.

Tracy's (2010) fifth criterion for excellent qualitative research is that of resonance, which works to affect the audience. Embedded within the smaller themes is the overarching theme of relatability. I chose to write about examples that I felt others could relate to. I also chose to omit stories that were relevant, but harmful in some way, to my audience and/or participants.

The sixth criterion, Tracy (2010) suggests, is that the research makes a significant contribution, and asks whether the study can "liberate or empower" (p. 845). Autoethnography can liberate the voices of the researched, as well as empower parents who would not have otherwise had a strong voice in this area of research.

The seventh criterion is ethical, which is to demonstrate respect for participants' stories and feelings over truth. I member-checked with participating mothers, but I also kept my husband and daughter in mind throughout the entire process. I wanted to protect their identities and feelings above all else.

Finally, meaningful coherence asks that the research "meaningfully interconnects literature, research questions/foci, findings, and interpretations with each other" (Tracy, 2010, p. 840). Using the literature to guide my sensitizing concepts, I worked to integrate my findings with theory in order to systematically analyze and make sense of my lived experiences.

Interviews

Autoethnographic work plays an important role in the conduct of research because each narrative "is open to multiple descriptions, diverging meanings, [and] varying storylines" (Bochner, 2015, p. 423). Incorporating the stories of others demonstrates the similarities and differences in parents' perceptions within the shared context of childhood disabilities. Autoethnographers do not always incorporate the narratives of others into their work; however, this process was an important part of making sense out of my own experiences. I chose to do interviews because I had come to appreciate — even depend on — the stories of others who have shared similar experiences to my own. It is only through the process of interviewing with this project in mind that I can share some of those stories with a larger audience. This paper demonstrates how shared experiences lead to community building and the development of social support systems.

Participants and procedures. After receiving approval from the Institutional Review Board (IRB) (Appendix A), I asked three mothers of children with DDs (with whom I already had connections) if they would like to participate in my autoethnographic research project. Informed consent forms (Appendix B) were provided and discussed, and pseudonyms were picked out for each mother and their children before the interviews began. The first two interviews were conducted face-to-face, and the third over video chat. Interview locations were chosen by the participating mothers and lasted between 90 minutes to two hours. Narrative style, open-ended interviews were conducted, allowing the mothers to talk openly about their experiences in their own words, while also covering topics relative to their personalized experiences. While I had an idea of what I wanted to ask (see interview protocol in Appendix C), my questions were formulated naturally throughout the interviews. Examples include: "What was it like for you when you first received your child's diagnosis?", "Tell me about what kinds of support you receive and from whom," "How do you talk about your experiences with others?", "What are your biggest fears regarding your child's DDs?", "What do your friends and/or family members say about the way you parent your child with DDs?" and "What kinds of special treatment do you give your child with DDs and how do you feel about it?"

I would have liked to interview additional mothers; however, due to time constraints I had to narrow it down to three. I asked Diana, Alison, and Jenny because they know more about my experiences than some of the other mothers I would have liked to interview. Diana has two children but her youngest, James, lost oxygen during his birth, which quickly led to a cerebral palsy diagnosis. James wears orthotic braces on his legs and uses forearm crutches to get around. He has limited speech but is not cognitively impaired. Alison has a daughter named Clare, who has a chromosome abnormality resulting in a variety of invisible disabilities (IDs), such as sleep apnea, dyspraxia, and learning disabilities. Clare requires close monitoring, including annual CT scans and EKGs because vital organs, such as the heart, bladder, and kidneys to name a few, can be affected by her unique genetic makeup. Jenny is the mother of two children with DDs. Jonah has severe CP, making him non-verbal and unable to control his body movements. He cannot walk or feed himself, so he will require full-time care for the rest of his life. Her daughter Jessica has what doctors consider high functioning autism (HFA). Jessica also has attention deficit hyperactivity disorder (ADHA) and sensory processing disorder (SPD).

To fully engage with the three participating mothers, each interview was audio-recorded on my password-protected device, then partially transcribed in a Word document that was kept on my non-networked, password-protected computer. I chose pseudonyms before the interviews began to protect the privacy of each participant, and all identifiable information was immediately camouflaged in my transcriptions, memos, and final document. After the interviews, I then wrote fieldnotes about them, which I kept in three different word documents (one per interview). I reflected on how the stories of others affected my perspective and identity, and whether there are any common themes found throughout the data. In addition to the data that focused on my experiences, inquiring about the experiences of others offered a layered account to the data (Ellis et al., 2011). I listened to each interview no more than two days after it was conducted. While listening, I partially transcribed the parts that had the most impact on me. I continued to type memos in the margins of these transcriptions throughout the autoethnographic process, as new ideas, themes, and concepts bubbled up. I made several passes at the data before listening to the recorded interviews a second time for clarity and/or additional details that I did not transcribe the first time. Finally, I combed through the transcripts and memos in search of themes unique to the interview data, and within my memos. I then compared these themes with the themes I found within my autoethnographic data (i.e., diaries, blog entries, texts, emails, social media posts, videos, and photos). Overlapping themes included fear, parenting behaviors unique to DDs, the parent-perspective of negative appraisal to positive reappraisal, relatability, and non-relatability. It was from these themes that my autoethnography emerged.

Once my analysis was made, I followed up with each informant through the process of member-checking for accuracy in my interpretations of their stories. Specifically, I followed the second criteria for quality research, rich rigor, which ensures transcript accuracy (Tracy, 2010, p. 841). Being that this is an autoethnography, rather than an interpretation of their experiences, none of my participants felt that they had been misrepresented. However, the follow-ups worked to further develop the connections and strengthen the relationships. This autoethnography gave them the opportunity to see how sharing their story worked to help another mother (me) make sense of lived experiences and achieve support through relatability.

Interviewing others has worked to not only add depth to my research but also give perspective and meaning to my experiences. According to Langellier and Peterson (2011), "storytelling is socially and culturally reflexive… [with] the potential to… give rise to new possibilities for other storytelling events and for how we participate in performing narrative" (p. 4). Reporting on a variation of experiences from multiple mothers offers a pivot point from my own experiences about the parent-perspective of caring for a child with a DD.   Finally, as a mother who has felt both isolated and empowered throughout my experience of parenting a child with a DD, my autoethnography demonstrates how the act of sharing stories has doubled as a source of support.

Analytic Process

It is one thing to sit down and pour your memories out onto paper; it is another thing to pull them apart with an analytic eye. Ellis et al. (2011) explain that “autoethnography is both process and product” (para 1). Both intrapersonal and interpersonal, this type of research takes on the form of an evocative narrative (Ellis et al., 2011), while also interpreting the sociocultural meaning of the author’s personal experiences (Chang, 2016). To achieve this, I organized all my data into two groups, self and other. As the piles grew, so did my fieldnotes. In a project such as this one, examining the ongoing experience of parenting a child with DDs, it is difficult to determine when the gathering of data should stop so that the inductive analysis can begin. The scope of this project is only as big as my experiences go thus far. My story will continue far beyond this paper, and new experiences will continue to affect me. However, in order to complete a product, I eventually had to stop collecting data to code. In the next two sections, I will describe how I went about coding my data, as well as how I achieved my inductive thematic analysis.

Coding. First, I organized my data into two sections: (a) existing data pulled from my fieldnotes relating to diaries, blogs, emails, and other sources of self-reflection, and (b) collected data from interviews of other parents. The process of open coding as described by Emerson, Fretz, and Shaw (2011), which is to read through all my fieldnotes line-by-line making memos of any emerging themes, as well as consistent and inconsistent ideas, helped me to reflect on my data as a whole. Once I completed that phase of coding, I began the next phase of focused coding, where I went through my fieldnotes again line-by-line, but this time with a fine-tooth comb to pinpoint a more focused set of connecting topics and themes (Emerson et al, 2011). I kept track of what the data was telling me by creating color-coded integrative memos throughout my processes of coding (Emerson et al., 2011).

Inductive thematic analysis. After combing through the data and coding for concepts, I began my interpretation of the data into themes. Using Tracy's (2013) guide for "visual data displays" (p. 213) to help organize my findings. Themes were chosen according to recurring concepts then guided by my sensitizing concepts based off my literature review.

One of the recurring themes I found in my data was fear. Specifically, I wrote about fear in my autoethnography because the coding and analysis revealed a progression of fear that has developed within me over time. While analyzing my early writings from the time my daughter was in the hospital with ADEM, there was very little talk about fear; instead I was much more pragmatic, writing about the logistics of Lily's medical care. Even my text messages to my mom were more about Lily's status rather than my feelings. Perhaps I needed to distract myself from this fear with knowledge, and so I dove into my own mini medical school approach, viewing my experience from the lens of a physician rather than one of a worried parent. However, what was inconsistent in my data was that other mothers do not share the same intense fear as me. I chose to include the concept of fear as a major theme in my autoethnography because it demonstrates a variety of communication theories at play, while also showing how communication can lead to changes in perception and behaviors. In the following paragraphs, I will flesh out these examples more explicitly.

As I conducted, transcribed, and coded my interviews, I constantly reflected on my own experiences and emotions, and then coded them as well. I analyzed what the other mothers talked about to see where and how relatability took place, not only in dialogue, but also in my own sense of identity. I asked myself, “what does the data say?” “How does the data make me feel?” “How does it change my perceptions, sense of belonging, and communication behaviors?” In my autoethnography, I point out times of relatability, as well as times of non-relatability. One major finding is how not relating to one mother can lead to isolation, while not relating to another can lead to clarity. Specifically, my coding showed a lot of feelings of isolation with mothers with typical children; however, this was not the case with mothers of atypical children. This led me to analyze what language was used, as well as what kind of communication behaviors were displayed by each parent type to determine whether and how communication plays a role in such feelings.

I also began to engage closely with a couple other parents with whom I can directly relate. My interview memos demonstrate a sense of comfort and a calm after the storm. While these behaviors are new, I truly believe that at the very least, this autoethnographic process has helped me make sense of my experiences in a way that has led to more positive transformations. In fact, my most recent Google search was on disability policy rather than medical signs and symptoms.

Chapter 5

Researcher Reflections

I officially began writing this autoethnography about a year after my daughter's ADEM diagnosis. However, I began writing what would later become my "existing data" much earlier. Right after my first 3D ultrasound, I remember feeling worried about how my baby was already upside down at 27 weeks. I suppose I have always been a worrier but when I look at those photos today, I can clearly see that she already showed signs of craniosynostosis. No one caught it and she was not diagnosed until 3 months after she was born. Be it mother's intuition or my sentimental personality type, I felt the need to document everything about my daughter from that day on. I never had a plan in mind for these documentations so when I dove into autoethnography I was unprepared for how emotionally draining the process would be at times. Some moments were painful while others were joyful. Some analyses brought clarity while others brought confusion. This is life though; an unpredictable journey filled with an array of emotions and experiences. Doing autoethnography has led me to revisit and even relive past experiences. Doing autoethnography has also allowed me to step outside of myself to view these experiences from a researcher's lens. Like pieces of a scrapbook spread out all over the dining room table, so were my data and artifacts: Digital photographs, videos, emails, journals, text messages, and more scattered throughout my MacBook Pro. In a way, doing this autoethnography has been a lot like scrapbooking. Once the project is complete, you have a collection of memories that showcases a significant event or portion of your life.

Researcher Awareness

While doing this autoethnography, I found that the process of interviewing other mothers of children with disabilities was very enriching for me. During the recruitment stage, I knew I wanted to interview mothers that I had previously developed relationships with. Since this is an autoethnography, I wanted informants who already knew my background story. This allowed me to relate with them holistically without having to do much storytelling myself. I was able to engage in active and interactive listening (Lillrank, 2014). Specifically, I could put my own perspectives aside and really listen to what my informants had to say while also reflecting on their responses (Lillrank, 2014). As I predicted, the interviews I conducted felt very natural from the start. One informant commented on how she could open up to me because I have a similar story of my own. Each interview felt more like a conversation than an interview. Such organic dialogues were sometimes emotional for my interviewee but also for me as a mother. During these moments, I was careful not to turn the conversation to my own experiences even though they were relatable because I wanted to create an environment that encouraged them to open up about topics and feelings I may not have considered, which in turn allowed me to see my own experiences in new ways. For example, when Diana talks about wanting to change systems rather than her daughter's DD, I had an aha moment where I suddenly realized that I had been so wrapped up in my fears based on past experiences that I was failing to address concerns that could affect future ones. I have been so caught up in the moments of each day, that I have not taken Lily's future into much consideration. My initial emotional response to her statements was panic because it seemed to add to my already very long list of worries. How would I find the time? Where would I even begin? However, this idea was so new to me that I had more questions to ask than I did personal examples to share. Lillrank (2014) discusses the importance of creating "a mental space that oscillates between closeness and distance" by encouraging the informants to elaborate (p. 284). At first, this was difficult for me because I had pre-established relationships with these women and wanted to share and connect with them in the same way that they were doing with me. However, with practice, I got better at balancing the different kind of mental spaces that need to be present during interviews as opposed to during traditional conversations. This approach leads to a richer interviewee narrative since they do most of the talking, and I found that the more they shared, the more I learned about myself. Specifically, I learned that I am more caught up in the past than I am the future. This drives the fear in me that affects how I cope with current experiences. I also learned that not everyone shares the same fears as me, or as intensely as I do. This may be due to my daughter's severe illness or to the uncertainties that lie ahead. However, this could also be a sign of post-traumatic stress disorder (PTSD) that may require more professional support. This is a somewhat comforting idea because it says that the fear can be managed with a different kind of support.

Seeing myself through others. Earlier in this section, I described the process of autoethnography to scrapbooking. The shared stories of others worked to inspire me on what to include in my autoethnography. By interviewing mothers of children with a variety of differing DDs, as opposed to focusing on specific DDs, I learned that there are varying processes of positive transformation. Specifically, positive reappraisal and acceptance were apparent in all the mothers I interviewed; however, these transformations appeared to be unique to the disability. This can demonstrate the need for disability-general support and research, as well as disability-specific support and research. When a DD is strictly physical, meaning that there is little to no future health risks at stake, the transformation happened very early after diagnosis, whereas DDs associated with medical threats (e.g., seizures, organ failure) occurred more slowly and in stages. This finding was significant to my own story as it helped explain why my transformation process seems to wax and wane.

Chapter 6

My Autoethnography

My daughter Lily is the most wonderful thing that has ever happened to me. The day she was born was one of celebration, and I anticipated a lifetime filled with them: milestones, birthdays, and accomplishments, I just knew she was going to rock them all. What I did not anticipate was that we would not always celebrate alongside our friends, or in the same ways. We celebrated most of our daughter's milestones much later than the parenting books suggested. Anniversaries became just as significant as birthdays were, such as the anniversary of when she came out of her coma-like state from ADEM. And, we have celebrated accomplishments no one else would think to celebrate, like being able to swallow her food after being tube fed for weeks, and being able to hop on one foot. As a parent of a child who suffered a severe illness and who is not "neurotypical," or in other words developing typically, I have come to realize that my experiences make me who I am. It is like being immersed in a different culture; I have adapted to new ways of thinking and behaving. In a way, I even speak a different kind of language.

I have always wanted to share my story with others from the inside out, exposing the difficult realities underneath my brave face, while also sharing the beauty and the wonder of parenting a child with DDs. I did not originally plan to embed my story into a research project with theoretical sensitizing concepts; data sets, and interviews; however, I also was not ready to share my story through the nakedness of an autobiography. I liked the idea of making sense of my experiences through autoethnography, while also hiding behind the literature to a point. However, while conducting my literature review, I found that much of it conflicted with my story. So much of the literature on childhood DDs comes from a medical lens with an informative voice, rather than directly from the parent lens. I believe that autoethnography gives agency and credibility to these voices, which may otherwise go unheard. Throughout this chapter, you will hear the voices of four different mothers, including myself, sharing the experience of parenting a child with DDs. While my voice dominates the story, I hope it is evident how the other mothers inspire and empower me throughout my process of doing autoethnography.

Fear

I was having coffee with an old friend when my phone rang. I hate to interrupt a good conversation for a phone call but I must in case there is an emergency. I miss the days when the thought "emergency" did not immediately pop into my head every time the phone rang. I discreetly looked down at my phone while pretending to still be engaged in what my friend was saying. The caller ID showed that it was the school nurse. My stomach did a flip and I silently began to panic. Did she fall? Is she sick? "Hello?" I said, while trying to hide the shrill in my voice. "It's an automated recording reminding me that there will be no school tomorrow," I said, with a forced calm demeanor. I hung up immediately with relief. "Sorry, my caller ID said it was the nurse," I concluded before changing the subject.[1] As my friend continued with what she was saying, all I could think about was how I really need to change my contact list. The nurse called me once from the school's main line and now every call I get from them comes up as 'school nurse.' I live in a constant state of high alert and stress has become my second skin because of it. I wear it all the time and without it, I am not sure I would recognize myself.

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[1] In this instance, I was experiencing what Baxter and Montgomery (1996) would call the relational dialectic of openness–closedness and praxis as I chose to disclose only a portion of what I was experiencing. I wanted to share with her what I was really feeling, but I also did know how she would react or what our conversation would look like if I was to open up about my fear and anxiety. I wanted our conversation to stay light and easy, so I internalized my true emotions.

Lately, my husband has been telling me that I need a vacation. I would love a vacation. "Where should we go?" was my response the first time he made this comment. "No, *you* need a vacation… without us. You should go to Sherry's wedding in London and have fun with your friends," he said. As much as I wanted to go to my friend's wedding, the very idea of being an ocean away from my daughter was paralyzing.

It has been two years since my daughter became ill with ADEM and yet, the fear still lives aggressively inside me. She has subsequent coordination disorder called dyspraxia, which makes it difficult for her to plan, organize, and carry out physical movements. She no longer has an aid with her at school so when the clock strikes noon, I know she is at recess and I make sure to have my phone close, and my shoes on - just in case. Playdates are also difficult for me. For example, I do not allow her to play at her friend Rune's house without me because he has steep wooden stairs leading to the playroom, and for some reason, the kids are obsessed with continuously running up and those stairs. Her freedom to be a kid is confined within my fear. On the rare occasions when I send Lily off on her own, I usually find myself in a state of constant worry.

I sometimes wonder if my mamma bear behaviors have gone into overdrive. I think about the way I care for myself in comparison to how I care for Lily. The other day while shaving my legs, I noticed a weird bump on my shin. I have had it for as long as I can remember and most of the time I forget it is even there. It does not hurt and I certainly have never felt the need to rush myself to a physician to make sure it is not cancerous or a genetic mutation that will turn into a third leg sometime in the future. So why do I panic if my child so much as blinks differently? Well, that is obvious – I love her more than I have ever loved anyone, and so enduring the traumatic experience of ADEM has led to an over-protective parenting style. The problem is, my fear has grown in such a way that it almost consumes me. At the same time, I work hard to protect her from sharing that fear with me.[2] Her life is filled with activities and travel, and I am comfortable with this as long as I am present. When my fear does prevent her from doing something, like playing over at Rune's without me, I always come up with a reason that is not related to my fear or her or DDs: "I really wish you could play at Rune's today but we are going to Trader Joe's." That day, I had no plans to shop but made them on the spot because I knew she would want to come with me. I struggle with wanting her to grow into her own unique individual while also wanting to always protect her.[3]

In addition to her immediate well-being, I also worry about the future. What barriers will she face as a teenager, and as an adult? I wondered if all mothers share this fear, so I asked my friend Diana. To my surprise, she does not. She explained that her son's diagnosis has never been life-threatening, so while she understands how I might wear the burden of fear, she does not worry about the day-to-day dangers or the future's uncertainties. My friend Alison, on the other hand, can somewhat relate to my fear, although perhaps not to the same extent. "My biggest fear is the unknown," she said. "Not knowing what could happen, what [Clare's] future looks like, not knowing if she will continue to grow physically or intellectually, the what ifs, the when

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[2] During this particular interaction, I experience the contradiction of openness-closedness (Baxter and Montgomery, 1996) as I manage what emotions and information I decide to reveal to my daughter. I want to be open and honest with Lily but I also want to protect her from my fear. Specifically, I do not want her to live in a world of fear like I do, nor do I want her to see me struggle with this fear. I do my best to shelter her from this emotion. I encourage her to live her life, while also working behind the scenes to protect her from dangerous activities when I can.

[3] Baxter and Montgomery (1996) would call this example a contradiction between connectedness and separateness. I want Lily to experience life and to be an adventurous and independent person; however, I also want to control as much as I can in order to keep her safe, and to keep my own nerves at bay.

should I panic, and everything that nobody can answer." She took a long pause before continuing, "The fear of the unknown is overwhelming at times."

Spoiled Alert

Recently we had to say goodbye to our beloved dog Zero. He was the cutest border-collie lab mix I have ever seen, but he was also too smart for his own good. Zero would have turned sixteen soon and being that my husband had had him since he was a young pup, one can only imagine the pain that this caused him. I, on the other hand, never really clicked with Zero. Like an arranged marriage, I began to love him over time, but he was never *my* dog. So, after ten years of putting up with his constant naughtiness, I was surprised at how emotional I became with his passing. This presence that had surrounded me for better or worse over the last ten years was suddenly gone, never to return. And furthermore, he had been a part of our family since the very beginning, so in a way, I felt as if a piece of our family was gone. The dynamic and routines abruptly changed, and this made me uncomfortable in a way that is hard to explain. I found that I no longer cared about all the Zero's nuisances. I just wanted him back. Death is the one single thing that cannot be undone. It is just so permanent and this concept terrifies me.

The passing of Zero brought back a floodgate of emotions from when my daughter first became ill with ADEM. I remember that first day in the hospital as if it were only yesterday. The possibility of her no longer being a presence in my life was unbearable. I was always a very attentive and loving mom, but I also got caught up in work and school. I was not always as present or patient as I could have been. As I stood over her in the PICU, all I could think about was how I had missed out on so many moments that I had taken for granted. Lily was in a coma-like state for weeks, which gave me a lot of time to think about what kind of parent I had been. Even though I knew deep down that Kevin and I were wonderful parents, all I could think about was every bad parenting moment I had ever had. I know that this is a crazy way to think; however, as my child lay in a hospital unconscious, it was easy to feel that I could have been better for her; and so, I promised myself that if she got through this illness, I would be perfect.

Lily has been out of the hospital for about two years now. It took time, but she has recovered quite well. To outsiders, it may appear that she is a normal, developing and healthy little girl. For the most part, this is true. However, she also has consistent monitoring by multiple medical and therapeutic specialists. If I am not taking her to an appointment, I am scheduling one. Sometimes I feel like I go to the hospital more than I do the grocery store. Because I feel bad that my daughter must be poked and prodded so regularly, I try to offset the stress of these hospital visits with rewards. For example, we always visit the gift shop after a doctor appointment so that she can pick out a "prize" for being so brave. And for those appointments where there is no need for bravery, well, she gets a prize after those visits too. I feel bad that she must miss school so much, and I feel worse that her day-to-day life is more challenging that it is for her peers. I watch her frustration as she struggles with the fine motor skills that her friends take for granted, such as putting together a puzzle. To make up for these mini adversities, I regularly treat her to something special after school like a playdate, an ice-cream, or a new toy. This "good mom" behavior may not be considered good parenting according to any parenting professional, and I do get a lot of flak from my friends and family for "spoiling" Lily, but I do what I can to ease the tensions in her life, and to make myself feel good at the same time.

I will admit that it is difficult for me to discipline my kiddo. I know it is my responsibility to teach her how to co-exist socially in the world so that she can do so as harmoniously as possible, but I also do not want to scold her knowing that she has been through so much. I make a lot of excuses on her behalf. To her credit, Lily is a very empathetic and mindful child. She is also fun and delightful to be around. However, I sometimes fear that I am instilling a sense of entitlement in her, and that my constant showering her in gifts and attention will do more harm than good. I began to wonder how other mothers treat their children in respect to the challenges that go along with a DD. As it turns out, I am not the only mother intervening in the daily challenges. Diana shared with me that she will even verbalize the DD as justification for any kind of special treatment, “I told his older sister to just give [the toy] to him because I mean, he has cerebral palsy, he can’t walk!” I found this refreshing since I tend to act more oblivious to my behavior rather than unapologetically owning it the way Diana describes. I know it is a little ridiculous to buy Lily something new every time we go somewhere. She has also come to expect it, which makes saying no especially difficult. So, what started out as rewards for her bravery and perseverance, has turned into an act of avoiding a total meltdown. “Oh, he manipulates me,” Diana said with a laugh, “but I don’t care, I just let him do it,” she told me. For the most part, I do not mind it either.

While later reflecting on this conversation with Diana, I was surprised that I did not ask her any follow-up questions, such as, “aren’t you afraid you will spoil him?” or, “how will you teach him about appreciation, work ethics, and disappointment?” I was surprised I did not ask such questions because these are the kinds of questions and comments that people have directed toward me in the past. I think I did not ask them because deep down, I know these kinds of questions do not always apply to atypical children. Lily learns these lessons daily from the world around her. No one else is giving her anything she wants, well except for her grandmas anyway. In fact, much of the time she gets left in the dust, without getting anything she wanted. She must work harder than most just to cross the monkey bars, open her lunch box, or get dressed. Furthermore, her life is filled with disappointments. She never wins a race or a game because she is not as fast as her peers. She also is not as coordinated, so after the piñata busts open at a party, her bag is the one with only a few pieces of candy while the others' bags are all bursting at the seams. These may sound like small things, but it is daily life for her, and it is heart-breaking to sit back and watch.

While Jenny and I were having coffee the other day, I asked her about what it is like for her as a mother to watch her kids struggle, specifically in social situations. "Well!" she said, in a loud voice that meant business, "let me tell you about this." She took a long sip of her latte and I just knew she was about to share something big. "Jessica's school is always putting on these little performances." Her face got serious, "this is great, right?" She continued before I could answer, "but the problem is, she is always the damn tree!" I was not completely catching on yet, so I just let her continue. "Yea, they make her this immobile tree that just sits in a corner doing nothing," she paused briefly before continuing, "without even a real role!" she exclaimed. I totally got what she was saying now because I have seen similar things happen to Lily. Jenny let out a deep breath of air and her voice went soft, "I know she can't like, say the lines or anything, but why not just let her be the flower that dances across the stage or something, ya know? Because she would totally love that." I could relate. With just a little patience and encouragement, Lily always shines brightly when given the chance; however, she is not always given that chance. Jenny had one last thing to say on the matter, "At the end of the day, I guess it's easier to pick the 'normal kid,'" she said while making finger quote gestures. This makes me wonder how often Lily's own unique talents are overlooked and how resistant the world will be adapting to her "special needs" when she cannot adapt to theirs. So, you know what? She deserves a place in the world where she is at the very center. I want to provide at least that much for her, even if it means excessive amounts of gifts and attention from her family.

When it comes to my daughter, there is so much that have I no control over. I cannot change her DNA, but I can redecorate her bedroom. I cannot take away the pain of every fall, but I can try to offset the pain with the pleasure of something sweet, like ice-cream. And if she were ever to become severely ill again, at least her last memory would not be me scolding her. It would be of something more positive. My empathy for her, as well as my fear of something going wrong, leads to me being overly doting, but I also enjoy it. Alison's daughter, Clare, has invisible disabilities (IDs) similar to Lily's. She told me that she shares the same feelings. She said, "Oh my gosh, the last week before Clare's surgery, she got soooo much stuff!!! I do it all the time with her!" She said this in a way that makes me think she also enjoys doting the way I do. "I feel bad that she has to go through this stuff," she justified. Talking with Alison puts my heart as ease because not everyone agrees with the degree to which I dote on Lily. Even my husband, Kevin, says that I need to stop buying her so much stuff.

Kevin and I balance each other out quite nicely. Wherever I have a weakness, he seems to have a strength, and vice versa. He thinks in the long-term while I get wrapped up in the short-term. I want to fix the "right now" and he wants to make things good for the future. However, my need to fix the now has been beneficial. In the case of Lily's diagnoses, Kevin thinks very practically, "well, she seems fine so let's just watch her and see," he will say. This thinking keeps us from rushing to the ER every week. However, it was my "right now" attitude that led to Lily's early diagnosis of craniosynostosis, which resulted in minor endoscopic surgery, as opposed to a series of major cranio vault reconstruction (CVR) surgeries.

I do not want to “spoil” her and I certainly want to teach her appreciation; but she works so hard every day. In many ways, I believe that she has already learned what appreciation means and how to show it. She appreciates her life, her health, and more than anything, her relationships with others.

Attached

My biggest concern is Lily’s wellbeing: You name it, I have probably worried about it. In my introduction, I mention that the sound of an ambulance makes me shudder. Whenever I hear the distant sounds of sirens grow closer, an uneasiness instantly washes over me. This emotion, however, is warranted by past experiences. When Lily was three, she pirouetted herself right off our bed, fracturing her left elbow on the floor. Then when she was six, she fell face first while climbing out of a friend’s car, which resulted in a buckle fracture on her right forearm. And just last summer, when she was seven, she broke and displaced both her ulna and radius bones in her right arm while dancing her heart out at an outdoor kids’ concert. For a girl who sometimes finds it hard to balance on her own two feet, the world is fraught with dangers.

This past September, Lily started off the new school year sporting her most recent cast. Knowing that this would not deter her from climbing up play structures and attempting monkey bars, I was feeling overly fearful about having her out from under my watchful eye. A few days into the first week, I was sitting on my porch when an ambulance sped by in the direction of Lily’s school. I spontaneously abandoned my book and quickly walked over to the intersection where to my horror, I watched the ambulance turn down the little residential street that her school sits on. I rushed back home, threw on my shoes, and made my way to her school. The ambulance was waiting out front. My heart started to pound. “Oh no, please do not let it be Lily,” I chanted to myself as I sped-walked toward the building. Once inside, I threw open the office door while blurting out, “is everything ok?!” The look of confusion on the receptionist’s face was the first indication that the ambulance was not meant for Lily. “Yes, a child fell on the playground but he is ok,” she explained. A combination of both relief and embarrassment swirled around inside me as I heard the male pronoun that assured me of my daughter’s wellness. “What can I do for you?” The receptionist asked me. “Oh…. uh,” I said, while digging past my mania for some sort of a coherent answer. “I, uh… I just forgot something,” I mumbled as I walked out. Feeling like I still needed validation, I briefly peeked into Lily’s classroom where she sat safely on the carpeted floor amongst her peers. I sighed out loud with relief before questioning my sanity. Months later, I was thumbing through my diary and noticed that the weeks leading up to this experience were filled with appointments at Children’s Hospital for routine check-ups and preventative care. It was interesting to take what I thought of as an isolated experience, and view it from a wider lens. Our daughter was still healing from encephalitis, had a broken arm, and was being tested for genetic abnormalities. It suddenly became apparent to me that all these medical visits and procedures were probably taking a toll on me.

Before ADEM, everything Lily ever had was chalked up by medical professionals as a fluke and easily fixable. Her skull was prematurely fused at birth (craniosynostosis), which could have led to pressure on the brain. However, two weeks in Texas with a leading craniofacial surgeon and a twenty-minute endoscopic surgery to re-open the skull suture, and she was good to go. When she was three years old, she suffered from sleep apnea, making for a lot of restless nights and irritable mornings. As it turned out, her tonsils were as big as cotton balls, which explained why she snored like a bear. Two little snips later and she was sleeping, and purring, like a kitten. Her ADEM really was the first medical issue that threw us for a loop. It was not easy to explain or cure. We were forced to wait it out, and it has been a roller-coaster ever since. It has been two years, yet the whole thing still shakes me up a little. She is doing really well and the doctors say that ADEM is almost always "monophasic," or in other words, a one-time deal. But, I continue to hold onto her tightly both literally and figuratively. "Are you ever gonna let me go?" Lily asks me this on a regular basis. Squeezing her tightly with my arms wrapped all the way I around her I always respond the same, "never!"

Fix You

When you try your best, but you don't succeed
When you get what you want, but not what you need
When you feel so tired, but you can't sleep
Stuck in reverse
When the tears come streaming down your face
When you lose something you can't replace, could it be worse?
. . . But if you never try you'll never know, just what you're worth
. . . I promise you I will learn from my mistakes . . . And I will try and fix you
(Coldplay, 2005, track 4)

The day after Lily was born, her heart rate dropped down between 60 and 80 beats per minute (bmp). A normal sleeping heartrate for newborns is between 90 – 160 bpm. My husband had gone home to walk our dog Zero, so when they took her to the NICU I was left alone in the hospital room for the first time since becoming a mom. With the goal of warding off worry about my new baby, I turned on the television only to see a Coldplay song that would foreshadow what motherhood would become for me – a constant desire to fix my daughter.[4]

Lily has had seven surgeries, and countless EEGs, MRIs, and CT scans. She has been receiving physical, occupational, and speech therapies since she was a year old. More recently, she has begun monthly immunotherapy treatments. I have spent most of my time as a mother feeling like I needed to "fix" her.[5] The first four lines in Coldplay's song reminded me how hard she tries to do things independently, but which often leads to frustration. Examples include things like opening her milk at lunch and building with Legos. Her friends have gotten into the habit of helping her avoid such struggles, and I am also very guilty of this. Doing things for her has the short-term benefit of preventing frustration and saving on time, but the long-term benefits of patience and perseverance are limited by this help. I often find myself worrying about how she will handle herself out in the world when no one is around to help her. At one point I was worried that she would not be able to open the door unassisted in case of an emergency so I taught her how to climb out the window.

The next four lines demonstrate how I have felt as her mother. I know it is emotionally painful for her at times. I know that she lost some abilities when she became ill with ADEM and that she may always struggle a little. But I also know she is amazing and hope that she will always know this, too. I am learning as I go and I will make mistakes along the way but I will always be here for her. That day in the hospital when she was just a tiny baby, I grabbed onto

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[4] Here I began to create an image of what it meant to be a mom of a child with medical concerns versus one without, which Scorgie et al. (2004) would describe as the first process of transformation (image-making) in their parent transformation model. Later this image begins to transform from fixing to accepting.

[5] The high degree of medical and therapeutic interventions shapes the way I think about DDs, which McConnell et al. (2015) describe as the sociocultural perspective at work.

those words "fix you." It was not until very recently that I began to change my perspective on this idea of fixing her, which I will explain in the following paragraphs.

We recently found out that Lily has a chromosome abnormality. I was not sure if I wanted to have genetic testing done, but once we got the results back, so many things began to make sense. My friend Alison told me that she feels so much better knowing her daughter's diagnosis because now she can seek out the services that *will* be beneficial to her daughter's needs rather than contemplating services that *might* be beneficial. Clare also has a chromosome abnormality, which has sent her down a path of mysterious medical concerns. I asked my friends Diana and Jenny what the genetic experience was like for them, and was surprised to find out that neither one of them went that route because their children's diagnoses were clear from very early on. This could explain why I lacked the same confidence that Diana seems to have.

Diana's son James has cerebral palsy (CP), which makes it difficult for him to walk and talk. However, right around the time she realized her son was missing milestones is when they received the CP diagnosis. Diana said she always knew her child was different but the word disability wasn't part of her vocabulary. Once she got the diagnosis, she immediately started Googling the life span of a child with CP. She laughs now because she knows that despite his DDs, he will live an otherwise normal life, but at the time she said, "I just didn't even know what that meant!"[6] I can relate to those feelings; however, I am still neck deep in Googling. James requires a lot of therapy, orthotic leg braces, and an electronic speech device; however, he is cognitively on par with his peers and does not have any other medical needs or complications. "Basically," she said, "it is what it is." I am inspired by Diana's acceptance of her son's

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[6] The parent transformation model (Scorgie, et al., 2004) demonstrates the process of image-making and meaning-making that Diana went through after the diagnosis of her son's CP.

diagnosis and take notice in how she seems to focus more on how to fix systems rather than how to fix her child. Diana told me, "That's the struggle I really have, I mean his disability is what it is but I fight systems… like why is Medicaid is on the chopping block?" she exclaimed. "Those are the things I think about when I think of my son," she said.

I have been thinking about this a lot. I vote but have never been a political person, and so I am not as informed on policies that protect people with disabilities as I should be. If I want to really make a difference in my daughter's life, I should work harder at fixing systems and perceptions. While writing this thesis I am also knee deep in a study about microaggressions, which describes how society plays a role in the way an individual experiences their disability. I did not share any information about that study with Diana but she said something that had a deep impact on me.[7] "And society," she continued, "who do I have to fight to stop the thinking that disability is a bad thing. It is part of human identity," she explained. "As humans, we all become disabled… we all grow old." I have recently learned a lot about how society conceptualizes disability and so hearing Diana talk about the very things I am researching creates a fire under me to not let my work get buried in academia. I need to translate my research in a way that will impact everyday people, and in turn my daughter's future.[8]

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[7] Later in my autoethnography I describe tensions of relatability and non-relatability, a spinoff of Baxter and Montgomery's (1996) RDT, with mothers of typical children. When reading that section, remember back to this example where Diana and I do also fail to relate (on the topic of fear), but how I am inspired and empowered by this non-relatable conversation. Perhaps it is how she chooses not to relate. She explains to me why she does not relate, while also empathizing as to why I would experience so much fear. I am inspired by Diana to transform my outlook and my behaviors, while in examples with mothers of typical children, non-relatability leads to me feeling hurt and begin to struggle with tensions of openness-closedness (Baxter & Montgomery, 1996).

[8] Here I begin to see how my identity as a protective parent can transform into a person who can make a difference in society and in the future of my daughter.

I couldn't agree more with Diana but at the same time I wondered how she finds the time. For me, every spare moment seems to be filled with a doctor appointment or a therapy session. "I am exhausted," I told her. Then she shared with me something I could really relate to, "James recently told me on the way home from therapy, 'no more therapy'… so I stopped taking him. He's eight. It's his life. Why won't I let him live his life?" I later reflected on what Diana had said and it was then that I came to realize that I do not want to "fix" Lily, I just want to help her live *her* life to the fullest.[9] I am still working through how to achieve this, be it less therapy or more activism, but I hope that my perspective will continue to evolve as I look more closely at who she is and what she wants.[10] I know some therapy is necessary and I will continue to take her to her doctor appointments; however, she has also has the right to be herself and have a say (within reason) about what is most beneficial to her identity. Rather than trying to fix or manage her DDs, I want to move my focus toward fixing and managing the world around her. For example, I put her in hip hop classes to help with her coordination. She loves these classes and I can see how it helps her physically, socially, and emotionally. She is having fun and feeling more confident in herself as a dancer rather than a patient.[11] I eventually stopped taking her to physical and occupational therapy but I always had the mindset that it was a break rather than a break-up. Now I am beginning to see it a little differently. Diana replaced therapy with

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[9] Diana and I talk about choice-making, as described by the parent transformation model (Scorgie et al., 2004). We as parents make a choice at how we view DDs, as well as how we view our children and experiences involving DDs.

[10] In this case, I engage in image-making, meaning-making, and choice-making as described by the parent transformation model (Scorgie et al., 2004). I begin to shed my guilt and change the way I view my choices. Rather than viewing my experiences through the lens of healthcare professionals, I am making the choice to view them according to what is really best for Lily.

[11] Here I work out how to empower Lily to develop her own image-making (Scorgie et al., 2004) of identity. I am giving her agency over her life and allowing her to be comfortable in her own skin by doing activities that she loves to do with her peers, as opposed to overdoing conventional therapy (unless absolutely necessary), which is a socially stigmatized, and isolated activity.

swimming and gymnastics, “it’s finding what they like to do, you know?” She paused for a moment while I nodded in agreement. “Lily loves to dance so I put her in hip hop, which has helped her coordination so much,” I shared. “Exactly,” she agreed. “James loves swimming, so I put him in swimming,” she said in a matter-of-fact tone. I felt this weight being lifted off my shoulders as I listened to her. I have been agonizing over my decision to cut back on therapy in fear that my tending to her happiness is at the expense of potential progress. But then, she is making progress, so why would I want to put her through more than what is necessary? She deserves as much of a normal childhood as possible, and while I know this deep down, it took relatability and approval from another mother for me to stop doubting myself. “You find ways around it,” she said. “He will get there,” she continued, “it may take longer, but he will get there.”

Identity Crises

The day my daughter was born was a joyous one. Like many couples who have just had a baby, my husband and I held our perfectly typical infant in our arms. We did it. We were parents. The first few months felt like I imagine it does for any new set of parents. Our days were filled with excitement but really, she just slept a lot! I spent my days pushing around my precious cargo in her ultra-stylish stroller. I had coffee with my new mom friends and exchanged birth stories with my old ones. Life was perfect. However, as she grew, we noticed that our daughter was developing differently from our friends’ babies. On her first birthday, she could not sit up unassisted, stand, or even crawl. She had not even cut her first tooth yet. A relative gave us a card for her birthday that said, “The year of firsts! First smile, first tooth, first steps…” Well, at least one of those were true. If nothing else, she was a happy little girl. Lily was put into a program called Birth to Three, which is an early intervention program that helps children with developmental delays. So, she had delays, no biggie, right? The word delay has never packed as much of a punch as the word disability first did. We were never explicitly told that she has a developmental disability (DD) until after she became ill with ADEM, and then, her diagnosis was complicated and filled with uncertainties. The word delayed meant that she would hit her milestones and live the life of a typical child in due time; but the word disabled? Did it mean that she was "not able?" Unable to do what exactly? And what did this mean for Kevin and me, as her parents? At that time, I did not have any friends with children with disabilities so I had no one to turn to for answers and support.

My family is lucky to live among an embracing community; however, I have always needed something my friends and local community members are often unable to give me – relatability. There are a lot of differences that unfold when parenting a child with a DD compared to one without. Diana and I shared stories about the challenges of finding appropriate daycares and schools for our children, even when it means moving to new neighborhoods, which we both have done. Alison and I talked about the unknowns regarding our daughters' conditions. Having a child with a DD means that we take on all the typical parenting duties and concerns while also taking on a plethora of additional duties and concerns. For example, we had to find suitable after school care, but when we did they were reluctant to take Lily based on her IEP. We also go through the rigmarole of signing her up for summer camps every year while investigating about which ones will be safe for her. It can sometimes feel like having another part-time job, and for some, the care alone is a full-time job. Alison told me, "over the course of five years, we have seen over seventeen different doctors, therapists, [and] specialists." I have never thought to sit down and count all the doctors and specialists we have seen but I do keep binders that contain all her medical records. So far, I have two 3-inch thick binders that are stuffed full. I think about all the times that Lily has had to miss school due to an appointment, and not just ordinary appointments. Rather, Lily's appointments consist of MRIs, EEGs, ultrasounds, and immunotherapy, to name a few.

The day-to-day life of a parent with a child with a DD is just different. Diana told me about what it was like when her son first started going to school and she noticed that he was unable to keep up with his peers: "that's kinda when I really knew he had a disability." I can relate to this on a personal level. Most days, I forget that my daughter is different. I love her eccentricity, her spirt, and love for life. Also, she is still very young so the fact that she cannot ride a bike, or that she needs help getting dressed can be easily justified in my mind.

Social situations are probably the hardest for me as a parent because it is in these moments that I am reminded of Lily's DDs. For example, her peers are able make complicated macramé style friendship bracelets while Lily carefully focuses on manipulating a string into a simple overhand knot. At eight years old, Lily's peers want to engage in more dialogue but she still wants to imagine that they are dragons. These more slowly developing abilities, and her eccentric behaviors are subtle. In fact, when we are at home or with the right group of friends, they are hardly noticeable. However, when they are made apparent, my heart aches for her. "It's not easy," said Alison, "[we] have to deal with the everyday life, it can be so stressful and exhausting, and not being able to talk to someone about it that truly understands makes it even more difficult to deal with."

I have done so much talking about my experiences and concerns, as well as all the joys of raising Lily. Yet, I continued to feel isolated because I was discussing these things with people who did not truly understand. It is not that they did not want to, they just could not, which often led to awkward social encounters that left me feeling insecure and alone. Eventually, I stopped sharing. However, this social strategy only backfired, because then I was not talking at all. I went mute and became very introverted, which is not the kind of person I have ever identified with. During this time, I was working on my undergraduate degree and enrolled in a course about intercultural communication. Being the world traveler that I always was, I was excited about this class. Perhaps it was a way of reviving my former nomadic identity, but it felt refreshing to have a group of people that I could relate to. Furthermore, since none of these fellow students were parents (that I know of), there was no pressure to talk parenting shop of any kind. However, my identity bubble was burst halfway through the semester. During a class activity, we were to privately write down three interesting facts about ourselves. The instructor compiled all of the facts onto a sheet of paper for the following class, and handed them out around the room. The goal of the activity was to try and match all the interesting facts with their interesting individuals. My three interesting facts where that I lived in China for 20 months, lived in Paris for two years, and was in a motorcycle accident in India. Needless to say, no one guessed any of my facts. Instead, one after another approached me with the same two questions, “do you like anything pumpkin?” and “do you like scented candles?” This experience was crushing. Neither of those facts are even remotely interesting, at least not in the context of a 30-something nontraditional student parent. As it turned out, both of these interesting facts belonged to a very athletic guy in the room. This made for an interesting context for him, but I was right back where I had started, identity-less.

Before becoming a parent, I was a wanderer. At one point, I spent five consecutive years abroad immersing myself in the cultures and languages of the world. I had a strong sense of self, and I was extremely happy. When I met Kevin, we continued the journey together, living in New York City and Portland, while traveling South East Asia and Europe in between. We decided to come home to Milwaukee after becoming pregnant with Lily. We decided it would be best for her grandparents to establish a relationship with her. However, our plan was always to stay for one year, then hit the air. Europe, Asia, or South America, we did not care but we knew we wanted to travel the world with our daughter in tow then settle down somewhere in Europe in time for her to go to school. Life does not always turn out the way one intends it, especially when your dreams are less mainstream. We manage to travel to Europe every year with Lily. We even lived in Paris with her for one year and went to Mexico twice. Other than that, Wisconsin has one of the leading Children's Hospitals in the country, both of our families live nearby, and all of Lily's procedures and appointments are paid for. We still hold onto the dream of relocating to Europe someday, but for now, we are here because it is what is best for Lily.

A lot has changed for me over the years. As much as I want to identify as the bohemian world traveler that I am at heart, I no longer am that person. So, who am I? I am a mother, which is the most magnificent journey one can take; however, I do not always identify with the traditional motherhood lifestyle made up of neurotypical children. I am still trying to navigate it all. I am not a career mom or a stay-at-home mom. I am a student mom, which only worked to isolate me more until graduate school. As an undergrad, I was older than most of my TAs and it was awful. As a graduate student, my professors are my age, and many of them mothers. Even some of my peers are parents, which gives me a sense of belonging; something I never had during my undergraduate studies. As I settle into my Northshore community, I continue to navigate my identity and how I communicate differently within each community. I am learning to divide my identity. In this way, I hope to become more open to making different kinds of connections that serve different purposes and fulfill different needs because not everyone is going to “get it.”

Support Seeker

I have experienced how support and understanding are two different concepts. I have friends who are very supportive; however, they are not always intuitive. Sometimes I really must spell it out for them, which is not always easy to do. For example, a popular birthday party destination place is at an indoor bounce house. The kids absolutely love it, including Lily. But for me, this place is my worst nightmare. Not only do I worry about her breaking her neck but I also stress out over the dozens of other children who run and jump around wildly. At places like this, Lily is always the kid who gets hurt. Someone knocks her down or plows over her. Most of the time it is nothing but a bump; but because we have made multiple trips to the ER from broken bones or gashes large enough for stitches, I am in constant stress. So, when a parent tells me it is a “drop off” party and that I should leave my daughter in the care of a host with ten other children to look out for, well I cannot do it. Explaining this to other mothers is difficult when they reply with, “she will be fine!”

It took me almost two years to realize that when I find myself in need of support, I usually ruminate on my emotions silently while outwardly going about my day as normally as possible. I believe this is because having a friend who is willing to listen, does not mean that they always know how to respond. Sometimes opening up can lead to salt in the wound. I remember one day last year chatting with another parent after school while our children played on the playground together. She was going on and on about her daughter’s success in reading and math, “the stuff is just too easy for her,” she said, as my heart sank lower and lower into my chest. At that point in time reading was a real challenge for Lily and math caused her so much anxiety that she began complaining of tummy aches before school. I did not share my emotions with this parent but I did mutter something along the lines of, "I wish it was that easy for Lily." Her response was both startling and hurtful although she meant no harm. "Well, Lily's a special case."[12]

I have thought a lot about community over the years and what it means to be part of one. We are a traditional nuclear family by definition, but I feel like we are somewhat living a nontraditional family lifestyle, which makes everyday talk both easy and difficult.[13] I spoke with my friend Jenny about how parents of children with DDs relate with families who have typical children. She shared with me how she talks to her closest mom friend at her daughter's school. "Well our daughters are in the same class [at school] so we talk about projects and the teachers… [but] I don't really bring up stuff she can't relate to because it will just make me feel…," Jenny paused for a long time trying to think of a word to describe her emotion, "I don't know, bad I guess," she concluded. Jenny has two children and they both have DDs. Her daughter Jessica has high functioning autism and her son Jonah has severe CP. I asked her if they ever talk about Jonah or if they ever have playdates outside of school. "We do sometimes [have playdates] but usually at a friend's house when my husband can be home with Jonah, …and we never talk about his CP but she will ask how he is doing and I know she means well but I don't know, it just feels weird to talk about him because she always looks so concerned… it's just part of life for me,"

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[12] Here I experienced the sociocultural perspective (McConnell et al., 2015) of DDs through another parent labeling my daughter as "a special case."

[13] This tension within my everyday talk can be explained by Baxter and Montgomery's (1996) dialectical tension of openness-closedness. I struggle intrapersonally with everyday talk with others because it is difficult to know when the conversation will lead to levels of relatability or the contrary. Furthermore, this tension arises because these kinds of non-relatable topics are often psychologically painful to me. I find myself hesitating before speaking, or sometimes regretting it when I do.

she said with a laugh then continued, “I really like her so we just talk about other stuff.”[14] I can relate to that too. I have had friends show concern over issues that do not concern me at all, like Lily’s inability to ride a bike. She is still mastering the training wheels while her peers have been riding confidently without them for years. I hate seeing her struggle but I am more concerned with her emotions than I am her abilities because I know she will be able to do these things — it will just take her longer to get there. What I really need to talk about are the issues I am struggling to process, like the findings of her latest genetic test, and my emotions surrounding these findings. There have been times when despite being surrounded by supportive friends, I felt completely isolated. This was because socially I felt alone in the experiences I was having. Diana said to me, “not everyone lives in Holland.” “Not everyone would even know what you are talking about,” I responded, delighted that she knew the essay.[15]

I’m from Holland, Too

As a parent of a child with DDs, I feel like I am walking off the beaten path with very few road signs to lead me along the way. For a long time, I did not know who to talk to, or even how to talk about my experiences. All I ever wanted was to feel understood. As a parent whose child was unable to meet milestones in the traditional sense, engaging with the parents of typical children has been a complex and sometimes painful process both emotionally and socially.

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[14] What Jenny describes, is an example of what Baxter and Montgomery (1996) call the dialectical tension of autonomy-connection. I reflected on how where I often experience the tension of openness-closedness, Jenny described the tension of autonomy-connection. I began to consider the idea that it is ok to be close to someone, and yet not feel the need to share everything with them. In turn, I believe this approach could affect how I experience the tension of relatability and non-relatability, which I flesh out further in the following footnote.

[15] These are examples describing tensions of relatability and non-relatability, which falls under Baxter and Montgomery’s (1996) relational dialectics theory. In the earlier example of openness-closedness, I struggled with tensions of when and what to share. I wanted so badly to relate, but also fear the conversation would lead to non-relatable communication exchanges, resulting in another tension I call relatability and non-relatability.

Since communicating more with other parents whose children have more in common with mine, I have come to accept that Lily will accomplish what she needs to accomplish when she is ready to do so. For years, I would compare her to her typical peers and I would lose sleep from all the worry that goes along with that. At the time, it was easier for me to think that she was a typical kid who had some bad luck (i.e., craniosynostosis) that led to her delays. Specifically, I blamed her being late to roll over and sit on her post-craniosynostosis-surgery helmet that she was forced to wear to reshape her skull. I blamed her far-sightedness on the craniosynostosis, and that became the excuse for why she did not crawl until she was 14 months old (soon after she got glasses). Everything stemmed back to craniosynostosis for me. And while some of this may have some truth to it, I was unable to see anything more until she became ill with ADEM. This was the one thing that I could not explain. It was then that I really felt alone. I did not know who to talk to. I could no longer relate to my peers. As it turned out, craniosynostisis was not the reason for her DDs, but rather the result of something bigger.

Twice now, I briefly mentioned one of my favorite compositions called "Welcome to Holland" by Emily Perl Kingsley (see Appendix D for full essay). More specifically, the author describes how raising a child with a disability is like planning a fabulous trip to Italy but unexpectedly landing in Holland. In her essay, everyone is bragging about their wonderful time in Italy while she is left to buy new guidebooks and learn a new language in Holland. That lost dream of being in Italy is very real and even painful at times; however, she describes how lovely Holland is once one settles down there, for "Holland has windmills, …tulips [and]… Rembrandts." I love this essay because it creatively demonstrates how isolating the experience of parenting a child with a DD can be, but it also points out the beauty of it. While raising a child with DDs, I may always wonder what life would have been like had I landed with the majority in Italy; but then I can't imagine a life anywhere other than where I am.[16] Lily has a sincere excitement for life and she sees beauty in everything. The most important point of Kingsley's essay is that it exists, which means that I am not in Holland alone; and for most of us Hollanders whose friends and family members are off living in Italy, the sentiment of having shared experiences is a powerful one. While it is important to note that Holland is filled with diversity just in the way that DDs encompass an array of differences, it is also valuable to understand that there is still a common language spoken here in Holland, which offers the opportunity to build a supportive community, which without, I do not know where I would be. As I continue to locate others who had landed in *Holland*, I also continue to stop trying to turn windmills into coliseums (or Holland into Italy).

My days are filled with appointments, evaluations, and worries, but they are also filled with love, joy, and accomplishments. I am lucky to have a handful of new friends who can directly relate to the ups and downs of parenting a child with DDs. I once told a dear friend whose son is autistic, "I hate birthday parties." I didn't have to say another word. She immediately burst into tears and hugged me and we did not need to talk about it any further.[17]

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[16] This essay is an example of a parent's positive reappraisal (Garland, Gaylord, & Park, 2009), in which they can reframe to see the positive aspects of any situation.

[17] Miller-Day (2004) would call these scripts: the kind of communication exchanges that are learned through time and interaction with another person. When people can relate on a personal level, as in the case of parents of children with DDs, these communication scripts come naturally within the interaction.

Chapter 7

Discussion

Much of the literature suggests that parenting a child with a DD is an adversity that needs to be managed or corrected. The stories shared with me by other mothers offer a very different outlook. While this autoethnography is limited in the amount of data that it provides, the narratives of three other mothers in addition to my own is a start toward awareness of the parent-perspective.

From a methodology standpoint, my interviews demonstrate the vital role they can play in the process of sensemaking while doing autoethnography. According to Gubrium and Holstein (2002), “interviews are central to making sense of life” (p. 30). Not all autoethnographies include the voices of others through interviewing. Some writers stick to telling their own story using fieldnotes (e.g., Ellis, 1995). For me, however, the process of interviewing was an impactful way for me to make sense of my experiences as a mother of a child with DDs. I learned that these mothers do not experience fear in the same way or to the same degree, but as mothers we all experienced parent transformations (Scorgie et al., 2004) as we developed our parent-identity within the context of our children’s DDs. Furthermore, I learned that relatability is important when parenting a child with DDs, which was what I struggled deeply with. I have experienced feelings of isolation or being disconnected from others due my inability to find relatability, which I believe demonstrates a divide that is formed once a parent has an atypical child. It is a feeling of being outside the circle and not knowing how to get back in. Researchers should push for a better understanding of how to re/connect parents of atypical children with parents of typical children. Communication scholars would certainly be able to contribute a wealth of knowledge to this topic; social interactions exist only because communication does. During and upon reflection on these interviews, I felt a sense of understanding, community, and empowerment to not only be more secure in my own parenting behaviors, but also in my perception of self. My process of transformation is still in its early stages; however, I believe that this thesis demonstrates how doing autoethnography has worked to shift my perspective toward a more accepting and positive one.

The Autoethnographic Breakdown

In the following sections, I work to make theoretical sense of the experiences that I wrote about while doing this autoethnography. I look to the literature and my sensitizing concepts to analyze my experiences, as well as how the process helped me make sense of them.

Fear, relational dialectics, and identity. In Fear, I talk about my fear as a mother and how I worked to hide that fear not only from friends, but also from my daughter. Baxter and Montgomery's (1996) relational dialectic of openness–closedness is obvious in the way that I struggled, then learned to manage how much I shared and with whom. Having found other mothers who have similar experiences and who I can relate with has helped. However, the process of writing through these conversations helped me pull more meaning out of these exchanges, which helped me analyze my own experiences and behaviors in a less subjective way. Specifically, I began to see myself differently and I began to feel like a part of something bigger – something important. My data has revealed that despite the extensive amount of research I do, I have always lacked confidence in who I was as a parent, as well as how I was parenting.

This section also demonstrates the contradiction I experienced between connectedness and separateness (Baxter and Montgomery, 1996). I want my daughter to be strong and independent, but I struggle with letting her out from under my wing where I feel she is best protected. My identity as a protective parent seems to dominate this section; however, toward the end of the section I begin to see myself as someone who can impact society and in turn, the future of children with DDs. The process of parent transformation (Scorgie et al., 2004) really progresses as I analyze my conversation with Diana and reflect on what kind of mother I had been, as well as what kind of mother I want to be. While I continue to feel strongly about protecting Lily from the day-to-day dangers and struggles associated with her DD, I have begun to see that I can have more of a purpose. I can fight to change perceptions through awareness. I can fight for policies that protect and empower people with disabilities.

Contradictions, empathy, and perceptions. In Spoiled Alert, I talk about how I compensate for my lack of control over her DDs with gifts and attention. Parenting a child with DDs can look quite different from parenting a typically developing child. Parents may want to “make up” for the difficulties their child endures; however, it is also possible that children may require more help and/or attention than children without disabilities. I was doubting my parenting behaviors because I measured them against those behaviors of parents with typical developing children. However, I found comfort in knowing that other mothers of children with DDs share similar parenting styles to me. In a longitudinal meta-analysis of positive parenting behaviors toward children with a variety of DDs, Dyches, Smith, Korth, Roper, and Mandleco (2012) found positive parenting to be beneficial to the functioning of young children. Examples of positive parenting behaviors in these studies included praising and rewarding, engaging and responding, guidance and facilitation, empathy and understanding, and affection and warmth (Dyches et al., 2012). When I describe showering my daughter in attention, what I really mean is that I offer her an extensive amount of guidance, empathy, understanding, and affection, as described by Dyches et al. (2012). While some people may believe that I am “spoiling” Lily, I believe that for the most part, I am instilling a deep sense of confidence in her while also trying to make life a little sweeter.

Image, meaning, and choice transformations. In Fix You**,** I talk about shifting my perspective on fixing my daughter to wanting to fix the world she lives in. This process of transformations led to the positive reappraisal of how I viewed (and behaved in regard to) childhood DDs. In the beginning, my views of DDs were shaped by the numerous medical interventions that Lily received. As described by the parent transformation model as image-making (Scorgie, et al., 2004), I saw my daughter as someone who needed "fixing" and, I was the "fixer." However, through my interactions with other parents, I began to construct new images, or new identities, for myself and my daughter (Scorgie et al., 2004). Specifically, I was moved by the choice-making that Diana described. I, too, had made the choice to pull back on the amount of therapy that I dragged my daughter to, but I had not yet made the choice to view my daughter as an individual with the right to live her own life. Additionally, I struggled with seeing myself as a potential parenting failure rather than an empowering advocate for my daughter. Through talking with others like Diana, I found confidence in embracing who we are while resisting the urge to push back.

Tensions between relatability and non-relatability. In Not Everyone "Gets It," I discuss my two different support systems. The first support system is made up of friends who have typical developing children. These parents cannot directly relate to my experiences as a parent with a child who has a DD. In fact, there are times when everyday talk with these individuals is painful. However, these relationships are important to me and fulfill other areas of my life. The dialectical tensions between openness–closedness, autonomy–connection, and relatability–non-relatability are demonstrated in how my communication behaviors fluctuate.

Specifically, the autonomy discourse allows me to keep talk of DDs separate from talk of other child-related topics, while still acknowledging the connection in spending time together (Sahlstein, as cited in Baxter, 2011, p. 129). This may seem like a violation of support, however, maintaining a degree of non-relatability allows me to step away from discourses of DDs, and focus on talk surrounding other characteristics of my daughter.

There are times when I want to remain autonomous, and free from the influence and ideas of others regarding how I parent my child. As I learn to navigate through the different communicative infrastructures, these dialectical tensions may wax and wane throughout time. For example, I may open up about Lily's immunotherapy, but not about her chromosome abnormality. Currently, I choose not to talk about Lily's medical issues with those outside my parenting children with DDs community because I know that when I do, I often regret it. There is also a risk of being unintentionally hurt by the reaction(s) of someone who cannot directly understand, which can also lead to a strain on the relationship. The benefit from talking about my daughter's DDs is dependent on how my listeners respond (Pennebaker & Smyth, 2016). Talk among people within the DD community feels very different from the talk that unfolds with parents of typical developing children. It is a two-way equal exchange of support and knowledge. It can be informative, reassuring, refreshing, and even empowering because it offers relatability. I am able to talk more freely about the facts and/or my feelings surrounding Lily's DDs because there is no need to explain medical jargon or justify my concerns or behaviors.

In Not Everyone "Gets It," I focus most on the tension of relatability–non-relatability. Although this concept has not been described as a dialectical tension by Baxter and Montgomery (1996), I believe this captures how friends can want to relate deeply on one level while simultaneously not wanting to relating on another level within the same topic. For example, I may wish to discuss pediatricians but not specialists, how much we love our kids' teachers but not the most recent IEP meeting, and about the trendiest kid clothes, but not about sensory issues limiting the kind of clothing Lily will wear. While the goal in these conversations may be to focus my talk on non-DD topics others can relate to, I may also seek out non-relatability.

Relatability–non-relatability can be thought of as a sub-category under autonomy–connection, and can lead to openness–closedness. Before my daughter became ill with ADEM, I was open to everyone about everything in hopes to connect and make sense of my experiences through relatability. When I was unable to achieve this, I began to shut down, internalizing my emotional experiences. Managing openness–closedness and autonomy–connection worked to protect myself from failing to relate; however, this also felt like "subtle social handcuffs" (Pennebaker & Smyth, 2016, p. 118) since I was still wanting to relate with others. Recently, I have begun to actively seek out relatability through parents who share similar experiences, which has been a positive experience. My need for relatability on topics surrounding DDs is being fulfilled. However, there is another side to this. There are times when the conversation cannot move past relating and becomes stuck within the framework of disability. Make no mistake, I do not know how I would cope without this relatable talk; however, sometimes I need to talk outside the umbrella of DDs. The communicative environment can either be stifling or supportive of how I talk about my daughter. Non-relatability used to feel like my biggest component, but since being able to achieve relatability, I have also begun to welcome the concept of non-relatability. As a parent of a child with DDs, I spend an incredible amount of time researching DDs, thinking about DDs, and talking about DDs. There are times when I really need to relate with others about DDs, and there are other times when I want to step away from the topic. Non-relatability allows me not to talk about DDs, while focusing on other relatable subtopics.

Community and positive reappraisal. In I'm from Holland Too, I discuss how community works to embrace communication scripts enacted between parents who have shared experiences. According to Woodgate et al. (2008), parents can feel a loss in a "normal" way of life (pp. 1078-1079). However, new "normals" can be co-created through talk and relatability with those who share similar lived experiences. Miller-Day (2004) discusses how being in a relationship is a communication process made up of informative transactions between people. These "transactions" are born out of social interaction where people co-create and manage the interpretations of meanings (Miller-Day, 2004). Miller-Day claims that family cultures communicate shared meaning systems through scripts. These scripts are routine and patterned ways of communicating "appropriate relational behavior" (Miller-Day, 2004, p. 216). While Miller-Day focuses on family cultures (i.e., grandmothers, mothers, and daughters), I believe this concept also applies to other cultures, such as disability culture. The conversations between parents who can relate about childhood DDs and what it is like to be the parent of a child with DDs, are forms of meaning-making. There are a unique set of scripts that are learned, practiced, and matured as relationships develop (Miller-Day, 2004) between parents of children with DDs.

Being part of a community of parents who share in the experience of having a child with DDs offers a common language and shared social norms where the communication transactions between two mothers of children with disabilities unfold naturally. Before I made connections with others who share in the experience of parenting a child with DDs, I felt alone. I turned to the few parenting books I could find that addressed this issue. One such book, *Special Children, Challenged Parents: The Struggles and Rewards of Raising a Child With a Disability* (Naseef, 2001), was the first to indicate that I am not alone in my experiences. Writing from his own experiences as a practicing psychologist and father of a child with DDs, Naseef (2001) has a way with words that only a parent who has “been there” can. The following quote was taken from this book and embodies what the process of sensemaking has been like for me while doing this autoethnography.

> There are many lessons on this journey for connection and support as we are drawn together by our similarities, meeting through tears and laughter. It takes courage to acknowledge the hurt or grief and loneliness and to risk being hurt again. But that risk is necessary to get to the other side of sorrow. Whether we are related by chance or choice, we must learn to accept and honor our differences. When we do this, we can divide our sorrow, multiply our joys, and make connections to support us through a lifetime. (Naseef, 2001, p.172)

This quote is a message of hope for me, and I believe it echoes the concept of relatability that is so present throughout my autoethnography. It is risky, to open up and connect with others. However, I have found that these connections can not only be supportive, but also be empowering and uplifting.

Identity. The theme of identity emerged throughout my autoethnographic findings as I worked to make since of my experiences. I internally negotiated and re-negotiated what kind of mother I was to my daughter, as well as what kind of communication behaviors I wanted to display as a parent, and as a member of my community. Identities derive from our interactions with others (Schwalbe, 1993). Rocque (2010) describes identity as being dependent on the reactions of others as “self” is performed. Navigating social encounters can be complicated for anyone, but as I work to blend in with the other mommies in my community by relating about new math strategies and celebrating milestones, my identity is challenged. In some ways, I am a mom of a neurotypical child but in other ways I am not. What I know for sure is that I identify as a mother more than I do anything else. I just do not feel attached to any other identity (e.g., student, scholar, employee). Navigating how I could find relatability, support, and positive feedback was difficult because I was not surrounding myself with people who primarily identified the way that I do (i.e., a parent of a child with DDs). Was I going to be transparent about our differences as a family or was I going to be closed off? I struggled with how my identity should take shape as a parent of a child with DDs. For example, I compared myself (parenting behaviors) to parents with typical kids, which caused me to question my own behaviors and in turn, feel more isolated. As I become more involved with parents like me, I continue to go through the transformation of positive reappraisal.

Limitations and Implications for Future Research

The type of fieldwork conducted by an autoethnographer deviates from traditional research, which focuses on the other rather than the self (Ellis et al., 2011). Doing autoethnography is challenging because it must live up to both autobiographical and ethnographical expectations. Autoethnographers work to skillfully blend the two types of discourse to create a provocative representation of research from a different point of view (Ellis et al., 2011), which also makes a scholarly contribution (Chang, 2016).

There have been multiple autoethnographies written about illness (Chang, 2016), and while this method adds perspective to the field of health communication, it lacks collaboration with other disciplines, such as nursing (Parrott & Kreuter, 2011). This solo act of doing autoethnography can lead to a redundancy of “discoveries” being made across fields (Parrott & Kreuter, 2011). While my autoethnography pulls from the literature across fields, it is not necessarily interdisciplinary because I have conducted the research alone. My multidisciplinary approach to doing autoethnography can lead to misinformed or inconsistent use of terminology, which can limit translational research (Parrott & Kreuter, 2011). A future study may include working alongside scholars from other fields to co-create interdisciplinary informed research.

Autoethnography has been described by Wall (2006) as, "an emerging qualitative research method that allows the author to write in a highly personalized style, drawing on his or her experiences to… acknowledge the inextricable link between the personal and the cultural and to make room for nontraditional forms of inquiry and expression" (p. 1). Opening up about personal experiences is not always easy. First, as an autoethnographer, you must be sure about your purpose, and not just caught up in a "dear diary" like moment. Second, you must be sure that you really want to share such intimate details of your lived experiences; and with everyone. Third, mindfulness is key and can be overlooked when writing about the self. Specifically, mindfulness of the people in your life you choose (or do not choose) to write about. Family members and friends may feel hurt or confused by what you decide to, or decide not to, write about. Perspective of characters in the story may differ so it is important to describe scenes, memories, and emotions from your perspective as the writer. Furthermore, you must be mindful of all possible audiences. Not every reader will have the same philosophy, or share the same beliefs. For example, I wanted to write about how terrible a particular medical procedure is. This story is very relevant in my overall experience, but I chose not to include this since so many families make the choice to do this procedure. Every autoethnographer will have a different end goal. For me, it was to connect and relate with other parents of children with DDs.; therefore, I wanted to be careful not to isolate them. With all of these considerations in mind, it is important to understand how using the personal narrative in research can be limiting to the research.

Traditional research "require[s] researchers to minimize their selves" (Wall, 2006, p. 2). The nontraditional method of autoethnography requires just the opposite. It is not linear (Ellis, 2004; Ellis et al., 2011), and therefore, can lead you to places you may not have been prepared for. At times, it can even feel like a psychological time bomb. It can also be liberating and empowering. Ellis (2004) describes the process of doing autoethnography as going "into the woods without a compass" (p. 120). The autoethnographer should be prepared to get lost, and determined to find themselves. This being said, the time it takes to do autoethnography can also be a limitation if you are up against deadlines. My suggestion for future autoethnographic research interests is to know the risks, prepare yourself, and then sit down, write, and enjoy the journey.

Future Directions

Parenting a child with a DD is filled with experiences that cannot be understood by everyone. For those of us who live it, there seems to be an unspoken understanding. Membership to this exclusive community is not something any of us ever signed up for yet here we are, connected with each other in a web of relatability and sensemaking.

Translational research makes an important contribution. According to Parrott (2008), communication scholars immersed in the discipline of health communication are driven to do research since their findings can be translated into practice to improve lives. The next step is to create a translational piece written for parents by parents who have experienced, or are experiencing, childhood illnesses and disabilities. Hospital websites and pamphlets offer parenting resources on what to expect while in the hospital; however, this information is often generalized for a broad audience and while this information can be very helpful, it is based on quantitative data and lacks depth. My goal is to increase the degree of understanding through an autoethnographic lens (Patton, 2015) and provide a type of literature that combines real-life experiences with theory and research.

Parrott (2008) states, “participating in translational research as a health communication scholar often begins with a willingness to tackle new knowledge” (p. 3). Since I am both a communication scholar and a parent who has become educated in a variety of healthcare activities, I believe that I can offer a unique perspective to academia and families by turning my autoethnographic thesis into a publishable book.

Petronio (1999) explains that translational research must consider the audience. I spent countless sleepless nights reading various medical journals, autobiographies, and blog entries. I have been on the other end of discourse as a participating audience member. The combination of these two different types of texts helped me process and understand my experiences. Cragan and Shields (1999) discuss how people decrease uncertainty by sharing information within their group. I will extend this idea by saying that through the sharing of information, or by storytelling, we break down walls of isolation by acknowledging that we are not alone in our experiences. By publishing an autoethnographic book, I will blend academic research with my personal story to add something unique to the discipline of Communication and offer greater understanding that can work to improve the lives of others who are living through a health crisis.

Conclusion

My life changed in unpredictable ways when my daughter became ill with ADEM. Adjusting to that change is a process that cannot be wrapped up into one theory or neatly outlined in a simple pamphlet. Parenting a child with DDs has challenged me to explore my identity, alter my perceptions, and challenge the way I make meaning. In their book Opening Up by Writing It Down, Pennebaker and Smyth (2016) claim that writing can enhance the way we adjust to upsetting experiences and improve our overall well-being.

This process of autoethnographic sensemaking has offered a narrative that details my lived experiences with the purpose of improving the understanding of parental communication behaviors in the context of childhood illness and subsequent DDs. Fisher's (1989) narrative paradigm suggests that narratives help us make sense of the world in such a way that the story of self can relate to the lived experience of others. My hope is that autoethnography connects my experiences to others and that they will connect theirs to mine.

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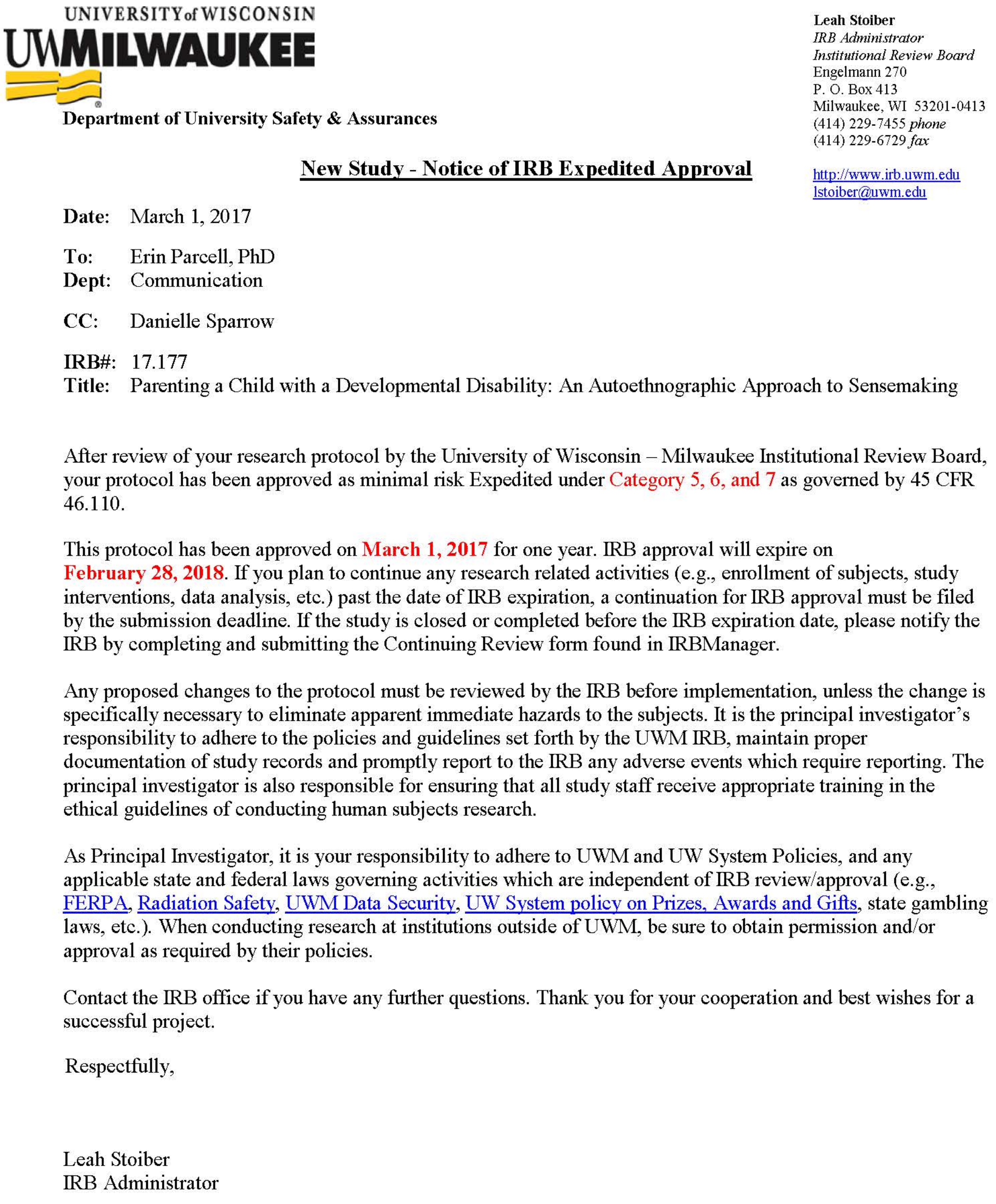
APPENDIX A:

IRB APPROVAL FORM



Department of University Safety & Assurances

Leah Stoiber
IRB Administrator
Institutional Review Board
Engelmann 270
P. O. Box 413
Milwaukee, WI 53201-0413
(414) 229-7455 *phone*
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http://www.irb.uwm.edu
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New Study - Notice of IRB Expedited Approval

Date: March 1, 2017

To: Erin Parcell, PhD
Dept: Communication

CC: Danielle Sparrow

IRB#: 17.177
Title: Parenting a Child with a Developmental Disability: An Autoethnographic Approach to Sensemaking

After review of your research protocol by the University of Wisconsin – Milwaukee Institutional Review Board, your protocol has been approved as minimal risk Expedited under Category 5, 6, and 7 as governed by 45 CFR 46.110.

This protocol has been approved on **March 1, 2017** for one year. IRB approval will expire on **February 28, 2018**. If you plan to continue any research related activities (e.g., enrollment of subjects, study interventions, data analysis, etc.) past the date of IRB expiration, a continuation for IRB approval must be filed by the submission deadline. If the study is closed or completed before the IRB expiration date, please notify the IRB by completing and submitting the Continuing Review form found in IRBManager.

Any proposed changes to the protocol must be reviewed by the IRB before implementation, unless the change is specifically necessary to eliminate apparent immediate hazards to the subjects. It is the principal investigator's responsibility to adhere to the policies and guidelines set forth by the UWM IRB, maintain proper documentation of study records and promptly report to the IRB any adverse events which require reporting. The principal investigator is also responsible for ensuring that all study staff receive appropriate training in the ethical guidelines of conducting human subjects research.

As Principal Investigator, it is your responsibility to adhere to UWM and UW System Policies, and any applicable state and federal laws governing activities which are independent of IRB review/approval (e.g., FERPA, Radiation Safety, UWM Data Security, UW System policy on Prizes, Awards and Gifts, state gambling laws, etc.). When conducting research at institutions outside of UWM, be sure to obtain permission and/or approval as required by their policies.

Contact the IRB office if you have any further questions. Thank you for your cooperation and best wishes for a successful project.

Respectfully,

Leah Stoiber
IRB Administrator

APPENDIX B

INFORMED CONSENT

UNIVERSITY OF WISCONSIN – MILWAUKEE
CONSENT TO PARTICIPATE IN RESEARCH

THIS CONSENT FORM HAS BEEN APPROVED BY THE IRB PROTOCOL # 17.177 ON 3/1/2017 FOR A ONE YEAR PERIOD

1. General Information

Study title: Parenting a Child with a Developmental Disability: An Autoethnographic Approach to Sensemaking

Person in Charge of Study (Principal Investigator):
Erin Parcell, Ph.D.
Department of Communication

Danielle Sparrow, M.A.
Department of Communication

2. Study Description

You are one of three mothers being asked to take part in a research study about how parents experience a health crises and/or the developmental disability of their child. I am asking you to take part in this because like me, you are a parent of a child who has experienced a severe health condition and/or developmental disability. Please read this form carefully and ask any questions you may have before agreeing to take part in the study.

Study description:
The purpose of this study is to add additional perspectives and knowledge to my research project, which will describe and analyze my experiences as a mother with a child who has gone through a health crises and who has developmental disabilities. To take part in this study, you must be the mother of a child who has gone through a health crisis and/or who has one or more developmental disabilities. The goal of this study is to better understand how mothers experience the health conditions of their children.

3. Study Procedures

What will I be asked to do if I participate in the study?
If you agree to participate in this study, I will conduct one interview with you, which is expected to last approximately one hour. You may be contacted once more by me for clarification and/or

follow-up questions. During the interview, we will discuss a time frame that works best for your schedule. The interview will ask you to share your personal experiences as a mother with a child who has, or who has had a severe health condition, and/or who has one or more developmental disabilities. During the interview, you will be asked to share your perspective on what it has been like for you as a mother of a child who has developmental disabilities. I may ask you some specific questions, which you can answer according to your comfort level. Finally, I will invite you to share any additional information you believe would be useful to my research. Questions will focus on your perspective, but will include inquiries about your child's past and current condition(s) and diagnosis. With your permission, I would also like to take an audio recording of each interview, which will be destroyed within one year from the date on this form.

4. Risks and Minimizing Risks

What risks will I face by participating in this study?
There is the risk that you may find some of the questions about your experiences to be sensitive and even emotionally and/or psychologically painful. However, you may decline to answer any questions you are not comfortable with and you are encouraged to take breaks if you need them, and even withdraw from the study if it becomes too painful. Any previous information that has been shared with me outside the interview will not be a part of this study. Those were private conversations that we shared, which are not part of my research.

5. Benefits

Will I receive any benefit from my participation in this study?
There is no guarantee that you will benefit from this study. Your participation will help social scientists learn something new and will possibly help other families who share similar experiences.

6. Study Costs and Compensation

Will I be charged anything to participate in this study?
You will not be responsible for any of the costs from taking part in this research study.

Will I be paid or given anything for being in the study?
You will not be paid for taking part in this research study.

7. Confidentiality

What happens to the information collected?
This consent form will be the only piece that has your name on it and it will be safely locked in my professor's cabinet in her office at UWM. All interview recordings will be labeled using

pseudonyms and you will be asked to use pseudonyms or generic terms (e.g., son, daughter, friend, school, etc.) in place of actual names during the recorded interview. The interviews will not be shared with anyone. All recordings and notes will be stored on my personal password-protected computer, which only I have access to. All notes will use pseudonyms and any identifying information will be heavily camouflaged from the beginning. All recordings and notes will be destroyed upon the completion of this research project or within one year from today's date. I will reflect on our conversation while I write about my own experiences. Some of your stories may be used and even quoted; however, pseudonyms will be used and all another identifying information you might share will be camouflaged (e.g., names changed). The final report will be submitted for my Master's thesis at the University of Wisconsin – Milwaukee. My thesis will not include any information that will make it possible to identify you or your child. Furthermore, if I decide to publish or present my research, you and your child's identity will remain confidential.

8. Alternatives

Are there alternatives to participating in the study?
There are no known alternatives available other than not taking part in this study.

9. Voluntary Participation and Withdrawal

What happens if I decide not to participate in this study?
Participation in this study is entirely voluntary. You may share as much or as little as you feel comfortable with. You may choose to skip any questions that you do not want to answer. If you decide to take part, you will be free to withdraw your participation at any time. If you decide not to participate, your decision will not change your relationship with me or with the University of Wisconsin – Milwaukee.

10. Questions

Who do I contact for questions about this study?
For more information about the study or the study procedures or treatments, or to withdraw our child from the study, contact:

Dr. Erin Parcell
UWM Department of Communication
Johnston Hall 226
eparcell@uwm.edu
(414)229-3127

Who do I contact for questions about my rights or complaints about my treatment as a research subject?
The Institutional Review Board may ask your name, but all complaints are kept in confidence.

Institutional Review Board
Human Research Protection Program
Department of University Safety and Assurances
University of Wisconsin – Milwaukee
P.O. Box 413
Milwaukee, WI 53201
(414) 229-3173

12. Signatures

Consent:

I have read or had read to me this entire consent form, including the risks and benefits. I have had all of my questions answered. I understand that I may withdraw from the study at any time. I am not giving up any legal rights by signing this form. I consent to take part in this study.

____
Printed Name of Participant

____ ____________________
Signature of Participant Date

Principal Investigator (or Designee)

I have given this research subject information on the study that is accurate and sufficient for the subject to fully understand the nature, risks and benefits of the study.

____ ____________________
Printed Name of Person Obtaining Consent Study Role

____ ____________________
Signature of Person Obtaining Consent Date

APPENDIX C:

INTERVIEW PROTOCOL

Institution: University of Wisconsin—Milwaukee
Research Study Title: Parenting a Child with a Developmental Disability: An Autoethnographic Approach to Sensemaking
Date: ________________________________
Interviewee: ____________________________
Interviewer: Danielle Sparrow, M.A., Department of Communication
Professor overlooking study: Erin Parcell, Ph.D., Department of Communication

Pre-Interview Comments: All parents being interviewed have had the diagnosis of their children having a DD for more than six months. All of the interviewees are being asked to reflect on memories as well as to describe what parenting a child with a DD is like for them today. All parents being interviewed are also acquainted with the interviewer, and know that the interviewer also has a child with a DD.

In order to be more present and engaged with you during this interview session, I would like to audio-record our conversation. The recording and any notes I take during this session will remain private and be stored on a password protected device that only I have access to. Please review and sign the consent form before we begin.

You are being asked to take part in this research study because you identify as a parent of a child with a developmental disability (DD). This research project takes on a holistic approach by focusing on the parent-perspective of caring for a child with a DD. Using a reflexive style of enquiry, the goal for this project is to use your narrative alongside my autoethnographic analysis of parents' experiences with parenting a child with a DD.

Possible Interview Questions

A. Background of Developmental Disability
   1. How long has your child had a DD?
   2. Has there been any diagnosed cause(s) of your child's DD?
   3. Can you describe your child's DD in detail?
      a. Probe: What kind of challenges do you feel your child has that are related to the DD? Does this differ from what healthcare providers predicted?
      b. Probe: What are your child's strengths?

B. Parent Perspectives: Child
   1. Tell me about some of your favorite characteristics of your child.
   2. What makes him/her unique to other children?

C. Parent Perspective: Emotions
   1. Describe what it was like when you first learned about your child having a DD?
   2. Describe how caring for a child with a DD feels for you?
   3. How do you feel about having a child with a DD?
   4. How do you feel about not having a typical child?
   5. Tell me about a time when you felt really proud of your child.

6. (If relevant) Can you tell me more about what makes having a child with a DD stressful? How do you handle this stress?
7. (If relevant) Can you tell me more about why you feel sad about your child's DD? How do you handle times of sadness?
8. What is one of your happiest memories with your child?
9. How do you celebrate these positive times (i.e. post on social media, share with others in talk)?

D. Parent Perspective: Relationships
   1. How has raising a child with a DD affected your parenting style?
   2. How has raising a child with a DD affected your child-parent relationship?
   3. How has having a child with a DD affected your relationship with your co-parent?
   4. How has having a child with a DD affected your friendships?
      a. Probe: Have you made any new friends since having a child with a DD? Tell me about those relationships and how you feel about them.
      b. Probe: Have any of your old friendships changed since having a child with a DD? How so?
      c. Probe: How much time do you spend with friends and what kinds of activities do you do together?

E. Parent Perspective: Identity
   1. How would you describe yourself before having a child with a DD?
   2. How would you describe yourself now?
   3. Tell me about a time when you felt helpless.
   4. Tell me about a time when you felt empowered, strong, or proud of yourself.
   5. How does it feel to engage with parents who have typical children?
   6. Does your experience change when you do not know the parents well? (i.e. classmates' parents vs. friends).

F. Communication
   1. How do you talk about your child's DD with your child?
   2. How do you talk about your child's DD with your parenting partner?
   3. Do you feel you talk differently about your child depending on who you are speaking with? Can you give me a couple examples?
   4. How do you talk about your child's DD with family?
   5. How do you talk about your child's DD with friends?
   6. How do you talk about your child's DD with members of the community (i.e. teachers, healthcare providers, therapists, other parents)?
   7. How has it felt talking about your experiences and child with me during this interview?

G. Social Support
   1. Tell me about what kinds of support you receive (i.e. online or community support groups, parent-to-parent support groups, family)
   2. What kinds of support feels the most effective for you?
   3. What kinds of support are least effective?
   4. How often do you seek support and what kinds of support do you seek the most?
   5. Describe the type of support you would like to receive.

Post-Interviewee/Interviewer Comments:

APPENDIX D:

WELCOME TO HOLLAND

By Emily Perl Kingsley

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

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

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

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

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

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

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

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

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

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

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